OXFORD BROOKES UNIVERSITY

Physical Activity of Adults with Intellectual Disabilities:

Feasibility and validity of measuring physical activity and physical activity intention and their relationship to the spectrum of Adults with Intellectual Disabilities

Yetunde Marion Dairo

Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

Department of Sport, Health Sciences and Social Work
Faculty of Health and Life Sciences

October 2017

This thesis is dedicated to my wonderful husband Shola, my two lovely kids, Tobi and Tara, and my parents, Eunice and Emmanuel Ipindumi

Abstract

In comparison to the wider population people with intellectual disabilities (ID) experience higher rates of morbidity and mortality associated with inactive lifestyles, however little is known about the pattern of their physical activity (PA). To address the inadequacies that currently exist around PA and those with ID, we need to better understand their PA levels to identify those who are inactive and the related factors. The four-part studies in this thesis aimed to establish PA levels of adults with intellectual disabilities (awID) across the spectrum. It also aimed to investigate the readiness to change PA behaviour in this population.

The first study, a systematic review of evidence for PA levels among awID found that in 15 eligible studies, comprising 3159 subjects, only 9% achieved PA guidelines. ID severity, living in care, gender, and age were independently significantly correlated with PA levels, the strongest predictor being ID severity (Beta 0.63, $p<0.001$). These findings were limited in context; none objectively measured PA in people with profound ID. This informed the second feasibility study, investigating assessment of PA across the spectrum using wrist-worn, 7-day accelerometers and the short form of the International Physical Activity Questionnaire (IPAQ-s). This revealed the difficulty in recruiting subjects across the full spectrum, and a difference in response rates between homes (16%) and residential-homes (4%): χ^2 (1) = 7.7, $p <0.05$. Nonetheless, 20 participants were recruited, and both PA measures were used across the ID spectrum, including in those with profound ID (n=5).

The third study investigated concurrent validity between the two PA measures; suggesting a substantial agreement between the accelerometer and IPAQ-s (k= 0.6, n = 16, $p < .05$) in identifying active participants, and a significant positive correlation between the sedentary time by the IPAQ-s and accelerometer (r = 0.50, n = 17, p = 0.04). This has implications both clinically and in the research environment as the study showed for the first time that the IPAQ-s could be used effectively to identify those that are active and measure sedentary behaviour across ID spectrum.

In the final study, PA levels measured across the spectrum using the IPAQ-s suggested low PA (39% active) and high sedentary behaviour (82% sedentary >3 hours/day) among awID (n=82). Multiple linear regression revealed that high ID severity is a significant predictor of low PA (Beta -0.28, $p<0.05$) and high sedentary behaviour (Beta 0.41, $p<0.001$). To investigate readiness to change PA behaviour in this group, the author developed a single-item PA intention measure (SPAIM). The construct validity and test-

retest reliability of the SPAIM were examined, and the relationship between PA intention and PA levels. The SPAIM was a reliable measure of the PA intention, with a strong, positive correlation between first and repeated measure (r_s =0.78, n=35, p<0.001). Additionally, linear regression revealed that PA intention significantly predicts daily sedentary hours (Beta -0.34, p<0.01).

This research showed that it is possible to measure PA levels across the ID spectrum, but the choice of measure is a major factor. It also highlighted a need for better engagement with carers and residential-home managers, to improve research participation by those with severe to profound ID. Moreover, although only a minority of participants were active, the majority had a positive PA intention. The amount of time spent being sedentary is the only variable related to PA intention. Overall, the evidence suggests that intervention studies aimed at reducing sedentary behaviour are urgently needed in this group. The sedentary hours/day could be a primary target for public health efforts in this population.

Presentation and Publications Relevant to Thesis

Publications

1 Dairo, Y. M., Collett, J., Dawes, H., & Oskrochi, G. R. (2016). Physical activity levels in adults with intellectual disabilities: A systematic review. *Preventive Medicine Reports, 4*, 209-219. http://dx.doi.org/10.1016/j.pmedr.2016.06.008

2 Dairo, Y. M., Collett, J., & Dawes, H. (2017*).* A feasibility study into the measurement of physical activity levels of adults with intellectual disabilities using accelerometers and the International Physical Activity Questionnaire. *British Journal of Learning Disability, 45:129–137.* https://doi.org/10.1111/bld.12188

Conference Proceedings

i. Dairo, Y. M., Collett, J., & Dawes, H. (2017). *Optimising Participation in Physical Activity Research for Adults with Intellectual Disabilities*. Oral presentation at the 19th International Conference on Physical Activity and Exercise Sciences, Barcelona, Spain, 25-26th May 2017. Published in: World Academy of Science, Engineering and Technology. International Journal of Sport and Exercise Sciences Vol: 4, No: 5. http://waset.org/abstracts/59083

ii. Dairo, Y. M., Collett, J., & Dawes, H. (2017). *The Test-retest Reliability and Construct Validity of a Single Item Physical Activity Intention Questionnaire for Adults with Intellectual Disabilities.* Oral presentation at the International Health Conference 2017. St Hugh's College, Oxford University, Oxford, UK. 30th June 2017

Presentations

I. Dairo, Y., Collett, J., Dawes, H. & Oskrochi, R. 2015, *'Physical activity levels in adults with intellectual disabilities: A systematic review',* **poster** presented at the Oxford Academic Health Science Network conference Oxford, 9th December 2015

II. Dairo, Y., Collett, J., Dawes, H. & Oskrochi, R. 2016, *'Physical activity levels in adults with intellectual disabilities: A systematic review'*, **oral** presentation at the 'annual research student symposium, Oxford Brookes University, 13th January 2016

III. Dairo, Y., Collett, J., Dawes, H. & Oskrochi, R. 2015, *'Physical activity levels in adults with intellectual disabilities: A systematic review',* **poster** presented at the Graduate College Annual Research Student Presentation Event, Oxford Brookes University, 3rd June 2016

IV. Dairo, Y. M., Collett, J., & Dawes, H. 2017, '*Optimising Participation in Physical Activity Research for Adults with Intellectual Disabilities',* **poster** presented at the

'annual research student symposium, Oxford Brookes University, 10th January 2017

Acknowledgements

Firstly, I would like to express my sincere gratitude to both my supervisors Dr Johnny Collett and Professor Helen Dawes for the continuous support of my PhD study and related research, for their patience, motivation, and immense knowledge. Their guidance helped me in all the time of research and writing of this thesis. I could not have imagined having a better supervisory team for my PhD study.

Besides my supervisors, I would like to thank the rest of the movement science group, particularly my PhD colleagues both past and present, for their insightful comments and encouragement, but also for the challenging questions, which incented me to widen my research from various perspectives.

My sincere thanks also go to all the study participants and their families and carers. Without their time and effort, this project would not have been possible.

I would also like to extend my thanks to Bucks County Council for granting me access to approach their clients, and to the staff at Advance Housing Oxfordshire who gave access to their clients and allowed me to use their meeting rooms for data collection. Equally, I wish to thank the Buckinghamshire and Oxfordshire community learning disability teams for their expert advice. Without the support of those services, it would not be possible to conduct this research.

Finally, I would like to thank my family members, especially my husband Shola and my kids, Tobi and Tara, for their sacrifices (financially and otherwise) and understanding. You were my rock throughout this journey, and without you, this would have remained just a dream. Thank you!

Contents

Glossary

150 mins MVPA	150 minutes of moderate to vigorous physical activity/week
Accelerometers	Accelerometers are wearable motion sensors that measure body motion (acceleration and movement). They can be used to assess physical activity and estimate energy expenditure
BMI	Body Mass Index
ID	Intellectual disabilities (also referred to as learning disabilities), defined as 'a significantly reduced ability to understand new or complex information and to learn and apply new skills', and it is diagnosed before adulthood
IDS	Intellectual disabilities severity (IDS), classified as mild, moderate, severe, and profound
IPAQ	International Physical Activity Questionnaire
IPAQ-s	The short, past 7-day, self/carer-administered form of the International Physical Activity Questionnaire
LIDT	Leicestershire Intellectual Disability tool
MCA	The UK Mental Capacity Act (2005)
MET	The energy cost of sitting quietly and is equivalent to a calorie consumption of 1 kcal/kg/hour
MVPA	Moderate- or vigorous-intensity physical activity
PA	Physical activity, defined as 'any bodily movements produced by skeletal muscles that result in energy expenditure.'
PA level	PA level is determined by the amount of time spent in a specified PA intensity threshold range, categorised as sedentary, light, moderate, and vigorous
PAG	Physical activity guidelines (PAG) is the recommended amount of physical activity that achieves health benefit

Sedentary behaviour	Sedentary behaviour is defined as ‘activities with energy expenditure ≤ 1.5 metabolic equivalents (MET) while in a sitting or reclining posture during waking hours’

List of Figures

List of Tables

Chapter 1. Introduction

This PhD research is about the physical activity (PA[1]) levels of adults with intellectual disabilities. Intellectual disabilities also referred to as learning disability in the UK, and intellectual developmental disorder in the U.S. is defined as 'a significantly reduced ability to understand new or complex information and to learn and apply new skills. The intellectual disability begins before adulthood, resulting in a reduced ability to cope independently, with a lasting effect on development' (World Health Organisation, 2015). In the UK, approximately 1.5 million people are living with an intellectual disability (Foundation for People with Learning Disabilities, 2012). This group of individuals has poorer health than their non-disabled peers with differences in health status that are avoidable (Krahn, Hammond and Turner, 2006; Emerson et al., 2014; Heslop et al., 2014). Although there are several reasons for these inequalities, low levels of PA are a major contributing factor (Robertson et al., 2000; Lin, Lin and Lin, 2010; Bergström et al., 2013; Hsieh, Rimmer and Heller, 2014).

In the wider population, there is an overwhelming evidence of the benefits of PA promoting health (Chief Medical Officer, 2011 ; Wen et al., 2011; World Health Organisation, 2016), reducing risk factors for diseases (Kyu et al., 2016), prolonging life (World Health Organisation, 2009; Wen et al., 2011), and improving cognitive function (Sefa and Neslihan, 2015). To date, however, relatively little is known about the effect of PA on the health of adults with intellectual disabilities. Although there is some evidence regarding the relationship between PA and health in people with intellectual disabilities (Robertson et al., 2000; Emerson, 2005; Wallén et al., 2009; Lin, Lin and Lin, 2010; Hsieh, Rimmer and Heller, 2014), the evidence is either limited to children and adolescence or focused on obesity. Additionally, the studies are cross-sectional studies providing one data point, which do not necessarily represent patterns over time. The absence of robust evidence in adults with intellectual disabilities on the impact of PA is compounded by the lack of information about their PA levels and how PA can be measured effectively. Before January 2015, there was no published systematic review of PA levels in this population, nor was there any published work on how to measure PA levels effectively across the intellectual disability spectrum. These gaps in the literature highlighted a need for further research to improve risk factor identification, minimise physical inactivity, and further advance understanding of the health-related impact of physical activity/inactivity in adults

[1] Physical activity (PA)

with intellectual disabilities. Therefore, the ideas for this PhD research were developed using a four-part series of studies to investigate PA levels among adults with intellectual disabilities and examine how PA and sedentary behaviour can be measured across the intellectual disability spectrum.

1.1. Background

In the current literature, the most cited definition of PA was published by Caspersen, Powell and Christenson (1985). They define PA as "any bodily movement produced by skeletal muscles that result in energy expenditure." (Caspersen, Powell and Christenson, 1985, p. 126). There have been many other definitions since, including the one by Bouchard and colleagues, which referred to PA as any body movement produced by the skeletal muscles that result in a substantial increase over resting energy expenditure (Bouchard, Shephard and Stephens, 1993; Bouchard, Shephard and Brubaker, 1994; Malina, 2004). The problem with the definition by Bouchard and colleagues is that of 'substantial increase' in energy expenditure. How much increase is substantial? As argued by Strath et al. (2013), most other definitions of PA are a derivation of the meaning by Caspersen et al. Thus, the author adopted the Caspersen's definition throughout this thesis.

The concept of PA is as old as mankind. Archaeological data suggest that all humans were hunter-gatherers before 13,000 BCE (Boundless, 2016). The hunter-gatherer way of life is based on the consumption of wild plants and wild animals. As a result of which they were often mobile (Walker, Walker and Adam, 2003; Stojanowski and Knudson, 2011; Boundless, 2016). Hunter-gatherers had to move around to get their food and did not have fixed settlements. As human society developed, and we moved from hunter-gatherer, pastoral, horticultural, agrarian, to the industrial and post-industrial world, our primary means of subsistence also changed. We no longer rely on gathering wild fruits and chasing wild animals (Stojanowski and Knudson, 2011; Boundless, 2016). These shifts in the primary means of subsistence had implications for other aspects of life, most notably a change from leading highly physically active lives to almost uniform sedentariness (Walker, Walker and Adam, 2003; Boundless, 2016). Inevitably, various healers and philosophers began to stress that long life and health depends on preventing illnesses through proper diet, nutrition, and PA (Centers for Disease Control and Prevention, 1999). PA is possibly the most important of all the components of a 'sensible lifestyle' being advocated (Walker, Walker and Adam, 2003). This has led to the interest

in PA alongside other lifestyle factors, but the question is how do we measure how active/inactive people are? This issue is one of the basis of this PhD research.

In modern times, the association between PA and health can be traced back to the work of Jeremy Morris and colleagues (Morris and Crawford, 1958; Strath et al., 2013). In their studies of coronary heart disease and PA of work, they observed that the incidence of coronary heart disease in bus conductors and postmen who delivered mails on foot was lower than that of the relatively inactive office workers such as bus drivers or postal office workers who spent most of their occupational time sitting (Morris et al., 1953; Heady et al., 1961). Although the studies by Morris and colleagues were retrospective in their design, and neither their methods or measurements were described in a way that it could be easily replicated, over six decades on, several studies, including prospective longitudinal ones, have confirmed the link between PA and health in a variety of populations (Department of Health, 2004; Clays et al., 2013; Richards et al., 2013; Lifestyles statistics team, 2014; Sefa and Neslihan, 2015). Moreover, in recent times, different studies have evidenced direct benefit of PA. For example, Sefa and Neslihan (2015) found that a PA programme of 30 minutes of walking and 30 minutes regular exercise, three days in a week increased the Mini-Mental Test Examination score of older adults from 20.6±2.4 to 24.3±3.6, a considerable and statistically significant ($p<0.05$) increase. Another study found that moderate-intensity exercise for as little as 15 minutes a day or 90 minutes a week, reduced the risk of all-cause mortality by up to 14%, and increased life expectancy by three years (Wen et al., 2011). Despite these benefits of PA, several studies have reported high physical inactivity among those with intellectual disabilities compared to the wider population (Robertson et al., 2000; Draheim, Williams and McCubbin, 2002; Frey, 2004; Emerson, 2005; McGuire, Daly and Smyth, 2007; Finlayson et al., 2009; Haveman et al., 2011; Phillips and Holland, 2011). However, most studies that measured PA in intellectual disabilities populations used instruments that are not validated, and different study designs and methods, making comparisons difficult (Temple, Frey and Stanish, 2006). Also, there are gaps in our knowledge of their PA. For instance, it is unclear what factors influence PA levels of adults with intellectual disabilities and how their PA levels compared with the wider adult population. Thus, this PhD sought to improve our knowledge of PA levels of adults with intellectual disabilities across the spectrum.

1.2. Physical activity measurement

For the assessment of PA, its dimension, as well as domain (the location or setting where the activity is carried out), are important in determining the appropriate measure (Strath

et al., 2013). PA can take place in any domain - recreation, transportation, household chores, and occupation (World Health Organisation, 2016). Its dimensions were described in detail by Strath and colleagues (Strath et al., 2013), as summarised below:

- Frequency: How often is PA undertaken?
- Intensity: Range includes sedentary, light, moderate and vigorous activities.
- Amount: Amount of time, distance, or steps over a specific time frame.
- Type: Exercise, sport, active commuting, etc.

PA is measured by different methods such as self-report questionnaires or surveys (Craig et al., 2003); objective measures such as pedometers (Tudor-Locke et al., 2011), accelerometers (Freedson, Melanson and Sirard, 1998; Esliger et al., 2011; Welch et al., 2013), and heart rate monitors (Freedson and Miller, 2000); PA logs and diaries(Tudor-Locke and Myers, 2001); observations, including direct observation (Sallis and Saelens, 2000), doubly labelled water (Westerterp, Wouters and Lichtenbelt, 1995; Maddison et al., 2007), and indirect calorimetry (Ohkawara et al., 2011). Research evidence suggests that observational methods, for example, the doubly-labelled water, direct observation, and direct and indirect calorimetry are the most valid criterion measures of PA (Welk, 2002). However, these methods are expensive, require trained professionals to administer, and are not practical for some applications (Mathie et al., 2004), and it is not feasible outside of the laboratory. When conducting PA measurement research, whether PA studies (either intervention or monitoring) or epidemiology studies, one has to balance accuracy with the practicality of the measuring instruments and cost (Tudor-Locke and Myers, 2001), especially when dealing with populations such as children, older adults, or individuals with a disability. This is because the measure may not be acceptable to them or even appropriate. The challenge is that greater accuracy requires increased cost and complexity (Prince et al., 2008).

1.2.1. PA levels

PA level is a common way of quantifying the measurable component of PA, and it is determined by the amount of time spent in a specified PA intensity threshold range, categorised as sedentary, light, moderate, and vigorous (Strath et al., 2013). The cut points for the different intensities depend on the type of PA tool used and the population they are used with (Chen and Bassett, 2005; Esliger et al., 2011; McGarty, Penpraze and Melville, 2015). For example, accelerometers measure body acceleration in gravitational units (g), in either one plane (usually vertical), two planes (vertical and mediolateral or

vertical and anterior-posterior), or three planes (vertical, mediolateral, and anterior-posterior) (Chen and Bassett, 2005; McGarty, Penpraze and Melville, 2015). The gravitational unit (g), is converted into an arbitrary unit referred to as 'count', which are used in estimating physical activity, such as energy expenditure or time spent in moderate to vigorous intensity, through the application of prediction equations or cut points (Chen and Bassett, 2005; McGarty, Penpraze and Melville, 2015; Esliger et al., 2011). These cut points and equations are developed by calibrating activity counts against a known biological measure such as the VO2 max (Esliger et al., 2011), and they are used to categorise PA intensities.

For self-report questionnaires such as the International Physical Activity Questionnaire (IPAQ), PA levels are derived from either the time spent doing certain intensities or calculating the metabolic equivalents (MET[2]) of the activities (www.ipaq.ki.se., 2005). MET is the ratio of a person's working metabolic rate relative to the resting metabolic rate. The World Health Organisation (2017a) defined one MET as the energy cost of sitting quietly and is equivalent to a calorie consumption of 1 kcal/kg/hour. However, MET values were intended for use in non-disabled adults who are 18–65 year old and do not reflect the energy cost of children and adolescents, older adults, and people with disabilities (Ainsworth et al., 2011). Lante, Reece and Walkley (2010) found that adults with intellectual disabilities expend significantly more energy than adults without intellectual disabilities for typical activities of daily living like sitting quietly and walking at 3.0 km/hour. For example, they expended 1.56 METs and 5.7 METs for sitting and walking respectively, compared to 1 and 2 METs for the same activities in the wider population, suggesting that published MET values can misclassify PA levels in adults with intellectual disabilities.

The World Health Organisation recommends PA levels for optimum health benefits as ‘at least 150 minutes/week of moderate-intensity aerobic PA or its equivalent’ (World Health Organisation, 2017b). This PA guideline (PAG[3]) is similar to the national guidelines in the UK, and it applies to the wider population as well as those with disabilities. (World Health Organisation, 2010; Chief Medical Officer, 2011 ; World Health Organisation, 2017b). Globally, there are data for PA levels for all ages, different races, and for men and women (World Health Organisation, 2010). There are also data for some distinct populations, for example, people with mental health issues (Janney et al., 2014; Vancampfort et al., 2016; Kruisdijk et al., 2017) and people with stroke (English et al., 2014; Sjoholm et al., 2014; Butler and Evenson, 2014). However, there is a paucity of data for adults with intellectual

[2] Metabolic equivalents (MET)
[3] Physical activity guidelines (PAG)

disabilities, in contrast to children and adolescents (Hinckson et al., 2013; Einarsson et al., 2016). Those studies that have reported PA levels of adults with intellectual disabilities (Finlayson et al., 2009; Finlayson, Turner and Granat, 2011; McGuire, Daly and Smyth, 2007; Emerson, 2005; Barnes et al., 2013; Dixon-Ibarra, Lee and Dugala, 2013) have either used tools not validated in intellectual disabilities populations or their samples were biased towards those with non-profound severities, as discussed in the next Chapter. These gaps in literature mean that the real patterns of PA levels of adults with intellectual disabilities are unknown.

1.3. Physical activity and sedentary behaviour of adults with intellectual disabilities

Previous studies show that adults with intellectual disabilities do not take part in regular PA (Robertson et al., 2000; Draheim, Williams and McCubbin, 2002; Frey, 2004; Emerson, 2005; McGuire, Daly and Smyth, 2007; Finlayson et al., 2009; Haveman et al., 2011). Also, that they have high levels of sedentary behaviour (Phillips and Holland, 2011; Melville et al., 2017). Physical inactivity and sedentary behaviour are globally associated with an increased risk of chronic diseases and poor health outcomes (Ding et al., 2016; Ford and Caspersen, 2012; Ekelund, 2012; Stamatakis et al., 2012; Owen et al., 2010). Physical inactivity is the 4th leading risk factor for global mortality, accounting for 6% of deaths globally (Public Health England, 2016). There is evidence that both the physical inactivity and sedentary behaviour reported in people with intellectual disabilities are prevalent pre-adulthood (Phillips and Holland, 2011; Shields et al., 2014). Sedentary behaviour is defined as 'activities with energy expenditure ≤ 1.5 metabolic equivalents (MET) while in a sitting or reclining posture during waking hours' (Sedentary Behaviour Research Network, 2012). Sedentary behaviour is an independent risk factor for all-cause mortality, premature death, and various chronic health conditions, including cardiovascular disease, type 2 diabetes and some cancers (Celis-Morales et al., 2012; van der Ploeg et al., 2012; de Rezende et al., 2014).

The lack of regular PA in this population is not surprising. As well as barriers that most people face that prevent them from being active, individuals with intellectual disabilities face additional issues (Bodde and Seo, 2009). There are physiological reasons that might cause inactivity, including but not limited to muscle weakness, hypotonia, and the presence of heart defects as well as circulatory and respiratory abnormalities (Dodd and Shield, 2005). Also, there are other broader determinants of PA relating to the environment, provision of care, and access to health-care services that could contribute to inactivity (Krahn, Hammond and Turner, 2006; Temple and Walkley, 2007; Bodde and

Seo, 2009). In addition to environmental, physical, and physiological barriers, other reasons for inactivity might be due to financial vulnerability (Hawkins and Look, 2006; Temple and Walkley, 2007; Emerson and Parish, 2010) and social disadvantage. For example, most adults with intellectual disabilities do not work, only 6.4% of those with intellectual disabilities are reported to be in paid employment (Health and Social Care Information Centre, 2011). To increase our knowledge of PA, and to change PA behaviour, policymakers need baseline data for PA levels (Hallal et al., 2012). The integrity of which relies on valid and reliable assessment (Bassett, 2000).

1.4. Justification for establishing physical activity levels of adults with intellectual disabilities

Not only do people with intellectual disabilities have poorer health, but also the costs of supporting an individual with an intellectual disability during his or her lifespan are much higher than for people without intellectual disabilities (Honeycutt et al., 2004). In general, the direct costs of physical inactivity to the National Health Service (NHS) annually is about £1.1 billion (Allender et al., 2007), with indirect costs to the society estimated at a total of £8.2 billion (Department of Culture Media and Sport, 2002; UKactive, 2014). Despite clear guidance about the need for an active lifestyle, most adults with intellectual disabilities seemingly fail to achieve the PA recommendations (Temple, Frey and Stanish, 2006; Phillips and Holland, 2011; Barnes et al., 2013; Dixon-Ibarra, Lee and Dugala, 2013). Hence, routine and reliable assessment of PA level in clinical and research setting is important to further understand PA behaviour, inform risk factor identification for low PA, and to develop more targeted PA promotion within intellectual disabilities populations. The author proposes that this PhD research will address this unmet need and is urgently needed now. The following studies will improve our understanding of PA levels and behaviour to inform risk factor identification for low PA and to develop more targeted PA intervention in adults with intellectual disabilities.

1.5. The aims of the thesis

I. To examine the published literature to establish PA levels, determine how they were measured and examine the reported factors that influenced them in adults with intellectual disabilities.
II. To examine the feasibility of measuring PA levels of adults with intellectual disabilities across the spectrum, namely response rate, recruitment rate, and acceptability of measures.

III. To examine the utility of using two different commonly used measures by determining the concurrent validity of the accelerometer and the International Physical Activity Questionnaire -Short version (IPAQ-s) in measuring PA levels of adults with intellectual disabilities.

IV. To measure PA and sedentary behaviour across the intellectual disability spectrum in a representative sample of adults with intellectual disabilities.

V. To examine the PA intention and the extent of its relationship with PA and sedentary behaviour of adults with intellectual disabilities.

1.6. Outline of the order of information in the thesis

- Chapter 2 (Study 1) – A systematic review of the published literature on PA levels of adults with intellectual disabilities to establish PA levels, determine how they were measured, and what factors influenced them in adults with intellectual disabilities.
- Chapter 3 (Study 2) – A feasibility study into the measurement of PA levels of adults with intellectual disabilities across the disability spectrum, including in those with a profound intellectual disability, using 7-day accelerometer and the IPAQ-s.
- Chapter 4 (Study 3) – The concurrent validity of the 7-day accelerometer and IPAQ-s in measuring PA levels of adults with intellectual disabilities.
- Chapter 5 (Study 4) – Cross-sectional study measuring PA and sedentary behaviour of adults with intellectual disabilities, and the development, construct validity, and test-retest reliability of a single-Item PA intention measure for adults with intellectual disabilities.
- Chapter 6 – Discussion of findings, limitation, clinical implications, and recommendations for future studies.

Chapter 2 (Study 1). Physical activity levels in adults with intellectual disabilities: A systematic review

2. Summary

Despite evidence that inactivity is a major factor causing ill health, there are gaps in our knowledge of PA in adults with intellectual disabilities. Before January 2015, there was no published systematic review of their PA levels. Therefore, a systematic review was performed from January-October 2015, comprising studies from across the globe to establish PA levels, determine how they were measured, and what factors influenced PA in adults with intellectual disabilities. Quality was assessed using a 19-item checklist. Meta-summary of the findings was performed and a meta-analysis of factors influencing PA using multiple regression.

2.1. Introduction

Historically, the diagnosis of an intellectual disability and its severity were based on significant cognitive deficits. Usually established through IQ test scores with a score of 50–69 classed as mild, 36–49 moderate, 20–35 severe and less than 20 profound (Harris, 2006; American Psychiatric Association, 2000). The same categorisation is supported by the World Health Organisation (1992), which classified IDS within the ICD-10 (F70–F73) criteria, broadly equating to IQ and developmental age as follows: profound (IQ < 20; <36 months); severe (IQ 20–34; 36 to <72 months); moderate (IQ 35–49; 72 to <108 months); and mild (IQ 50–69; 108 to <144 months). More recently, the American Psychiatric Association's DSM-5 (American Psychiatric Association, 2013) recommended that the severity of impairment be based on adaptive functioning (social and emotional maturity relative to peers) rather than IQ test scores alone. Hence, an intellectual disability is classified as mild, moderate, severe, and profound (Katz and Lazcano-ponce, 2008; Salvador-Carulla et al., 2011; American Psychiatric Association, 2013) based on the extent to which an individual is unable to face the demands established by society for the individual's age group (Katz and Lazcano-ponce, 2008; Salvador-Carulla et al., 2011).

Globally, estimates of prevalence of intellectual disability vary for several reasons, including methodological differences between studies (Harris, 2006; Maulik et al., 2011; Doran et al., 2012), the wealth of the country, and the age-group of the study population (Maulik and Harbour, 2010; Maulik et al., 2011; Harris, 2006). Maulik, et al. (2011) reported a prevalence of 16.41 and 15.94/1000 population in low- and middle-income countries respectively, whereas, in high-income countries, these figures are lower, with

an estimated prevalence of 9.21/1000 population. Additionally, they reported higher prevalence among studies based on children/adolescents (18.30/1000), compared to those on adults (4.94/1000) (Maulik et al., 2011). Importantly, these figures are set to rise due to increase in life expectancy in this group of people (Holland, 2000; Harris, 2006; Emerson et al., 2014). This has implications for people with intellectual disabilities who have poorer health than their non-disabled peers, with differences in health status that are avoidable (Krahn, Hammond and Turner, 2006; Emerson et al., 2014; Heslop et al., 2014). These differences start early in life, with a higher prevalence of diseases such as obesity, hypertension, and hyperlipidemia common among people with intellectual disabilities as early as adolescence (Lin, Lin and Lin, 2010; Wallén et al., 2009). While there may be several reasons for these health differences (Krahn, Hammond and Turner, 2006; Emerson and Baines, 2011; Heslop et al., 2014), low levels of PA are key lifestyle factors causing ill health and an increased risk of chronic diseases in people with intellectual disabilities (Robertson et al., 2000; Bergström et al., 2013). The medical and nonmedical lifetime costs associated with the diagnoses of intellectual disability are much higher than for people without intellectual disabilities with many associated with an inactive lifestyle (Honeycutt et al., 2004). These costs are substantially higher than those associated with the diagnosis of other disabilities (e.g., cerebral palsy, vision, and hearing impairments) and could potentially be reduced with lifestyle modifications (Honeycutt et al., 2004; Doran et al., 2012).

A physically inactive lifestyle increases the risk of non-communicable diseases, and increasing PA has been shown to improve health outcomes (Richards et al., 2013; Lifestyles statistics team, 2014). In spite of clear guidance about the need for an active lifestyle, several studies in the literature reported absence of regular PA in adults with intellectual disabilities (Robertson et al., 2000; Draheim, Williams and McCubbin, 2002; Frey, 2004; Emerson, 2005; McGuire, Daly and Smyth, 2007; Finlayson et al., 2009; Haveman et al., 2011). Compared with the wider population, there are gaps in our knowledge of their PA. For example, individual factors such as sex, race, and social status that have been shown in the wider population to influence PA levels are yet to be established within intellectual disabilities populations. To implement effective non-communicable disease prevention programmes, policy makers need data for PA levels (Hallal et al., 2012). However, before January 2015, there was no published systematic review of PA levels of adults with intellectual disabilities. A review by Temple, Frey and Stanish (2006), on PA levels in adults with intellectual disabilities, did not use systematic methodology. Out of the 14 papers included in their review, eight used questionnaires that were neither valid nor reliable and overall, their review data were informed by studies

set within a limited context, with high levels of bias and samples that were not reflective of people with intellectual disabilities. This gap in the literature highlighted the need for a systematic review to determine PA levels in adults with intellectual disabilities, and factors relating to this behaviour so as to improve risk factor identification and better target PA promotion in this group. It is hoped that the findings of the review will promote our understanding of the factors influencing PA levels and in turn inform interventions to minimise inactivity. Therefore, this review will aim to examine the published literature to establish PA levels, determine how PA levels were measured and examine the reported factors that influenced PA levels in adults with intellectual disabilities.

2.2. Methods

The review was prepared and reported with reference to the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' guidelines (Moher et al., 2009). A protocol for this review was registered with PROSPERO on 02/03/15, registration number CRD42015016675. Available at http://www.crd.york.ac.uk/PROSPERO

2.2.1. Identification of literature

Searches of electronic literature databases were conducted in January 2015 from the earliest available date. The databases searched were Cochrane Library, PubMed, Web of Science, CINAHL, and MEDLINE (the latter two via EBSCO). In order to ensure that no relevant studies were missed, additional studies were identified by hand searching reference list of reviews and research papers relating to PA in adults with intellectual disabilities. The searches were re-run in July 2015 just before the final analyses, but no further study was retrieved.

2.2.2. Search Strategy

In each database, terms for **intellectual disability** and associated synonyms were identified. These terms were then combined with search terms relating to **PA** and **PA level/ measurement**. Searches were limited to papers published in the English language, on humans and included adults (Appendix 1). Using the Boolean operator 'OR' resulted in a large amount of returned records majority of which were irrelevant. For example, in CINAHL database, 42,174 searches were initially returned. Consequently, the search mode was changed to minimise the number of irrelevant articles returned. For the CINAHL search string, once the Boolean operator was changed to 'AND' the search string returned fewer article (177). The host institution subscribes to MEDLINE and CINAHL through EBSCO. When two search strings are combined, duplicate entries are removed before the number of search results is displayed. EBSCO host does this automatically.

2.2.3. Screening and Eligibility

All articles identified by searches were exported to Endnote Web. Duplicates and irrelevant records were removed. Remaining records were screened by one review author (YD) to identify studies that potentially met the inclusion criteria outlined below (section 2.2.1). The full text of these potentially eligible studies was retrieved and independently assessed for eligibility by the same reviewer. A second reviewer (JC) blinded to the first author's selection, randomly selected 8 (24%) potentially eligible studies and independently assessed their eligibility. Disagreement between reviewers was resolved through discussion with a third reviewer (HD). Using Cohen's k (Cohen, 1960), a substantial agreement was found between the first and second reviewers ($k=0.8$, $p<0.05$).

Inclusion Criteria

1. Studies that quantitatively measured levels of PA in adults with intellectual disabilities (where intellectual disabilities is diagnosed using any recognised diagnostic criteria, or on a GP list of people with intellectual disabilities or identified as having intellectual disabilities by the social services department or using the specialist intellectual disabilities service or had done so in the past)
2. The following study designs were eligible for inclusion in the review: Cross-sectional, cohort, and case-control studies
3. Published in English between 2004 and the present
4. Peer reviewed
5. Included subjects that are aged 16+ (at least 95% of the participants are aged 16+)
6. Have primary research data.

Exclusion criteria:

1. Intervention studies (both field and clinical trials) and single case studies
2. Papers that were not published in the English language
3. Studies on children and young people up to 16 years
4. Grey literature, e.g., dissertations, conference abstracts, research reports, chapter(s) from a book, personal correspondence or commentaries, and policy documents.

Context

As discussed in Chapter 1, the working definition for PA was as described by Caspersen et al. (Caspersen, Powell and Christenson, 1985). Briefly, "any bodily movements produced by skeletal muscles that result in energy expenditure." (Caspersen, Powell and Christenson, 1985, p. 126).

The date limit for the searches was set between 2004 and the present because most older studies measuring PA levels in adults with intellectual disabilities used questionnaires and interview that were likely not to be validated. Consequently, for the quality assessment of the studies in this review, one of the criteria addressed the subject of instrument validity and reliability. Another reason for the date limit was that the narrative review in 2006 by Temple, Frey and Stanish (2006) covered all the relevant studies up to 2004. The author also excluded grey literature because of limited time and resources.

2.2.4. Quality assessment

In selecting the appropriate checklist to assess the quality of the records that were included in this systematic review, several other scales and checklist were considered, namely Cochrane risk of bias tool, QUADAS, Jadad score, Pedro scale, and Newcastle Ottawa scale. Some of the scale and checklists were designed for randomised controlled trials, but none of them are a valid measure of the risk of bias and quality with respect to the kind of studies that were included in this systematic review, i.e., cross-sectional and cohort studies. For example, in a study by Hartling et al. (2013), investigating the interrater reliability and validity of the Newcastle Ottawa scale that is used for methodological quality assessment of cohort studies in systematic reviews, they found the scale difficult to use, and decision rules vague even with additional information provided. They also found no association between individual items or overall score and effect estimates**.** Consequently, an existing checklist for cross-sectional studies was adapted for the quality assessment.

Each included study was critically appraised for its methodological quality using a 19-item checklist, which covers five domains: reporting, external validity, internal validities (bias and confounding), and power. Items 1-17 were adapted from a 27-item checklist developed by Downs and Black (1998). This checklist was chosen as its quality index had high internal consistency and good inter-rater reliability, and because it was designed for reviewing non-randomised controlled studies. It also has good face and content validity. Nine items from the original checklist were excluded as they were only relevant to studies investigating the effectiveness of an intervention and one item, the one relating to power calculation was adapted in line with the checklist developed by Bellet et al. (Bellet, Adams and Morris, 2012). An overall percentage score was awarded to each of the included studies based on the number of items in the checklist that was applicable to the study design.

2.2.5. Data Extraction

Data extraction was developed based on existing systematic review articles in related fields. The form was pilot-tested on three randomly selected included studies and refined accordingly. Data extraction was completed by one reviewer (YD). Extracted information

included: bibliographic details (author and year); the country within which the study took place; sample size and participants' demographic data including characteristics of the groups as well classification of intellectual disabilities severity (IDS[4]) (i.e. mild, moderate, severe, and profound); study design; measurement tools; inclusion and exclusion criteria; outcome measures; main results and issues raised in the discussion. Missing data were requested from study authors by e-mail.

2.2.6. Data analysis

A descriptive summary of the included studies was completed. A metasummary was performed structured around PA levels of adults with intellectual disabilities and its measurements. A meta-analysis was performed with a pooled summary of the variables and using simple linear regression models. The models were run separately for each of the independent variables (mean age, proportion of male, proportion living in care, and proportion with high intellectual disabilities severity) to determine the association between the percentage of participants achieving PAG and each of the independent variables. After that, a multiple regression model was used to examine the combined associations between all the independent variables and the percentage of participants achieving PAG. Results were expressed as regression coefficients representing the variation in the numbers achieving PAG explained by the regression model. All analyses were conducted using SPSS for Windows (version 22.0), and cases were weighted by sample size.

2.2.7. Physical activity guidelines

The current minimum weekly aerobic 'global PAG for Health' is that adults should do at least 150 minutes of moderate-intensity aerobic PA or 75 minutes of vigorous-intensity aerobic PA throughout the week or an equivalent combination of moderate - and vigorous-intensity activity. These activities should be in bouts of at least 10 minutes (World Health Organisation, 2010). These guidelines are like those used in many westernised nations (Chief Medical Officer, 2011 ; The Office of Disease Prevention and Health Promotion, *2008 ;* Australian Government Department of Health, 2014) and similar to those used in the included studies. The minimum PAG used in many of the studies was 150 minutes of moderate to vigorous physical activity/week (150 mins MVPA[5]). Some studies also used the number of steps/week as their PA criteria.

[4] Intellectual disabilities severity (IDS)

[5] 150 minutes of moderate to vigorous physical activity/week (150 mins MVPA)

2.3. Results

Study selection and quality assessment

Total records found were1319, and review flow is given in Figure 2.1. Fifteen studies were included in this review. The methodological quality of the included studies varied greatly, with none of the studies achieving 100% yes score in the 19-item checklist (Table 2.1).

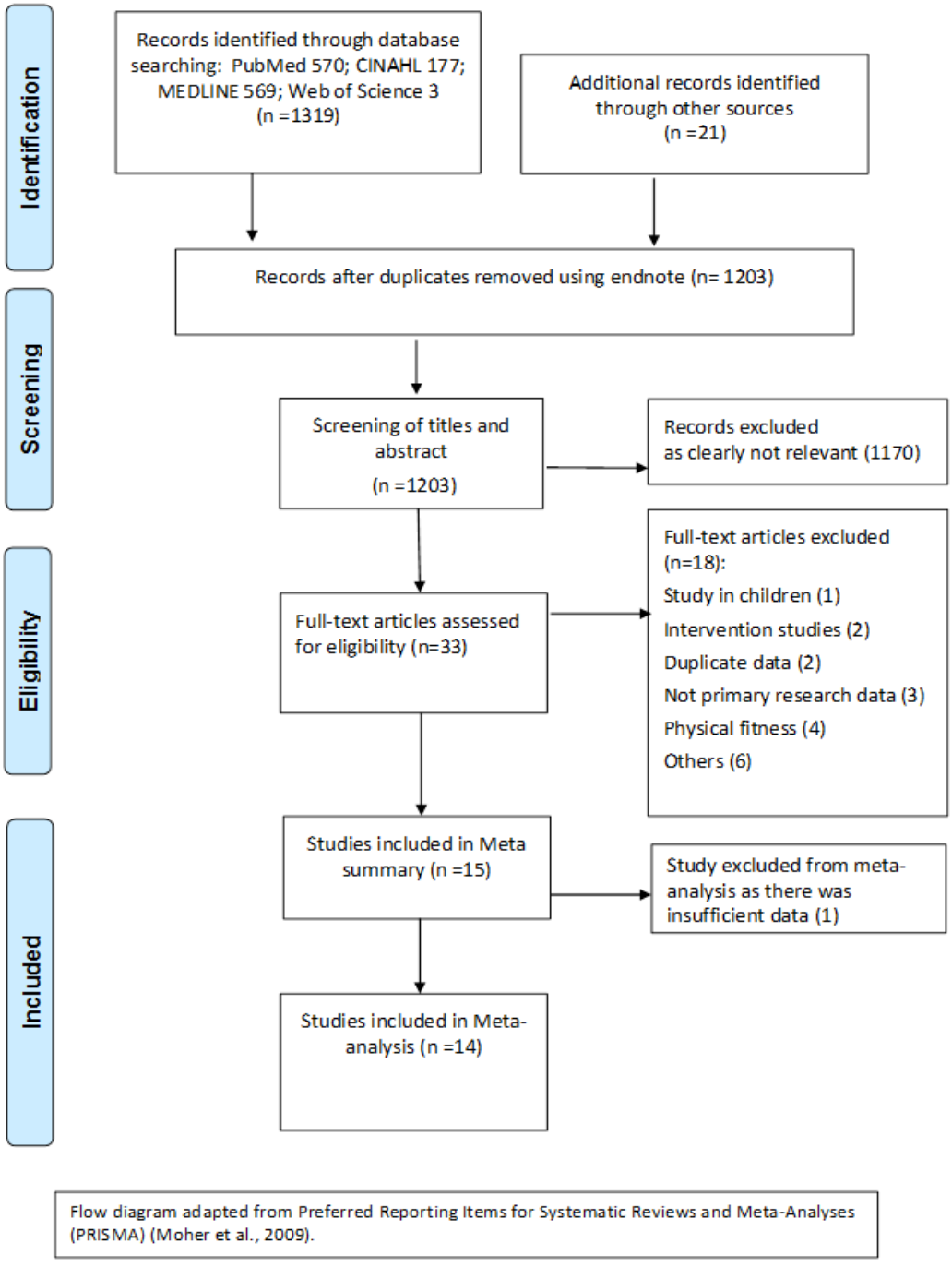


Figure 2.1 Flow of studies in the systematic review

Table 2.1 Critical Appraisal

	Study reference															
Criteria	Barnes ('13)	Dixonlbarra ('13)	Emerson ('05)	Finlayson ('09)	Finlayson ('11)	Frey ('04)	Hawkins ('06)	Higenkamp ('12)	McGuire ('07)	McKeon ('13)	Peterson ('08)	Phillips ('11)	Stanish ('04)	Stanish ('05)	Temple ('07)	Score[a] (%Y)
1. Is the hypothesis/aim/objective of the study clearly described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100%
2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	87%
3. Are the characteristics of the subjects included in the study clearly described ?	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	N	N	N	67%
4. Are the distributions of principal confounders in each group of subjects to be compared clearly described?	N	U	U	Y	Y	Y	U	Y	N	N	Y	Y	N	N	U	40%
5. Are the main findings of the study clearly described?	Y	Y	Y	Y	Y	Y	Y	N	N	Y	N	Y	N	N	N	60%
6. Does the study provide estimates of the random variability in the data for the main outcomes?	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	87%
7. Have the characteristics of subjects lost to follow-up been described?	Y	N	N	Y	Y	Y	Y	Y	N	Y	N	Y	U	Y	Y	67%
8. Have actual probability values been reported	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	93%
9. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	Y	N	N	Y	U	N	N	Y	Y	N	U	N	U	U	U	27%
10. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	Y	U	N	Y	U	U	N	N	Y	U	Y	U	U	U	U	27%
11. Were the staff, places, and facilities where the research was conducted representative of that in use in the source population?	Y	N	Y	Y	N	N	U	Y	Y	Y	Y	Y	N	Y	N	60%
12. Were the statistical tests used to assess the main outcomes appropriate?	Y	Y	Y	Y	Y	Y	N	Y	U	Y	Y	Y	U	Y	Y	80%
13. Were the measurement tool(s) used valid and reliable?	Y	Y	Y	N	N	Y	N	Y	N	Y	Y	Y	Y	Y	Y	67%
14. Were the cases and controls (case-control studies) recruited from the same population?	NA	Y	NA	NA	NA	Y	NA	NA	NA	NA	NA	Y	NA	NA	NA	100%
15. Were the cases and controls (case-control studies) recruited over the same period of time?	NA	U	NA	NA	NA	Y	NA	NA	NA	NA	NA	Y	NA	NA	NA	67%
16. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	Y	U	U	Y	Y	N	U	Y	U	Y	Y	Y	N	N	U	47%
17. Were losses of patients to follow-up taken into account?	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	87%
18. Was the number of subjects either >50 or was a sample size calculation provided?	Y	Y	Y	Y	Y	N	N	Y	Y	N	Y	Y	N	Y	N	67%
19. Did the subjects give consent prior to testing?	Y	Y	N	N	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y	73%
Score[b] (%Y)	94%	58%	59%	88%	76%	74%	35%	71%	53%	71%	82%	89%	35%	65%	53%	

NOTES: Score[a] (%Y), percentage of studies scoring yes for the respective criterion; Score[b] (%Y), percentage of total yes score achieved by each study; Y, yes =1; N, no =0; U, unable to determine =0; NA, not applicable therefore not included in the scores; Description of rows - see below

Questions relevant to Reporting (1-8)

Questions relevant to External validity (9 -11)

Questions relevant to Internal validity – bias (12 &13)

Questions relevant to Internal validity - confounding (selection bias) (14-17)

Question relevant to power (18).

Checklist criteria adapted from Downs and Black (1998) and Bellet, Adams et al. (2012)

Five studies scored >75% (Barnes et al., 2013; Finlayson et al., 2009; Finlayson, Turner and Granat, 2011; Peterson, Janz and Lowe, 2008; Phillips and Holland, 2011), eight studies scored >50%, but <75% (Dixon-Ibarra, Lee and Dugala, 2013; Emerson, 2005; Frey, 2004; Hilgenkamp et al., 2012; McGuire, Daly and Smyth, 2007; McKeon, Slevin and Taggart, 2013; Stanish, 2004; Stanish and Draheim, 2005a; Temple, 2007), and two studies scored less than 50% (Hawkins and Look, 2006; Stanish, 2004). Only 3 (Barnes et al., 2013; Finlayson et al., 2009; McGuire, Daly and Smyth, 2007) out of the 15 studies met all the criteria for external validity assessment items. There was evidence of high selection bias as demonstrated by the relatively low score concerning the questions addressing adjustment for confounding variables (Table 2.1, questions 4 and 16). Most studies did not describe the distributions of principal confounders in each group of subjects compared, nor did they investigate possible confounders or adjust for them in their analysis.

Study characteristics

The studies comprised 3159 adults with intellectual disabilities, aged 16 to 81years (mean age 45.99years, SD 6.79), 54% male and 46% female. Eighty-three percent had their IDS reported as 39% mild, 34% moderate, 23% severe, and four percent profound. Of the 28% asked about employment, 42% were employed. Table 2.1 summarises the result of the quality assessment, while Table 2.2 provides a summary of the bibliographic details as well as participants' demographic data. A summary of PA measurements and results of individual studies is presented in Table 2.3.

2.3.1. Physical activity level measurement

Methods used to measure PA levels are summarised in Table 2.3. Objective measuring instruments used were accelerometers and pedometers, while the subjective measuring instruments were diaries (Hawkins and Look, 2006; Hilgenkamp et al., 2012), and the following semi-structured interviews and questionnaire surveys: International PA Questionnaire (IPAQ[6]) (McKeon, Slevin and Taggart, 2013); PA Checklist Interview (PACI) (Barnes et al., 2013); PA scale (Emerson, 2005); National Health and Nutrition Examination Survey (NHANES) III (Stanish and Draheim, 2005a).

Six studies (Barnes et al., 2013; Finlayson, Turner and Granat, 2011; Hilgenkamp et al., 2012; McKeon, Slevin and Taggart, 2013; Phillips and Holland, 2011; Stanish and Draheim, 2005a) used both direct observations as well as either a survey/interview/diary.

[6] International Physical Activity Questionnaire (IPAQ)

Table 2.2 Summary of included studies

Bibliographic details		Sample size	Age range: mean (SD)	Level of Disability				Sex		Race				Residence			Employment		Risk factors for Cardiovascular Diseases					
Author & year	Country where study took place			Mild	Moderate	Severe	Profound	Male	Female	Caucasian	African	Asian	others	Alone	Supervised apartment/ residential	With family	Full/part time	Not working	BMI <20 (kg/m2) underweight	BMI 20-25 (kg/m2) normal	BMI 25-30 (kg/m2) overweig	BMI >30 (kg/m2) obese	Hypertension	Cholesterol level
(Barnes, Howie et al. 2013)	USA	131	18-65: 37.5 (11.8)	NR	NR	0	0	70*	61*	52*	76*	0	3*	2	63	66	NR	NR	0^	26*	105*	NR	NR	NR
(Dixon-Ibarra, Lee et al. 2013)	USA	76	20-77: 42.8* (7.80*)	NR	NR	0	0	48	36	72	2	1	1	17	50	9	55	21	2	23	26	20	NR	NR
(Emerson 2005)	UK	1542	16-75+: 49.3 (15.5)	504	443	441	NR	824	693	1485	10	9	10	0	1542	0	NR	NR	183	404	365	352	NR	NR
(Finlayson, Jackson et al.	UK	433	16-75* : 44.1 (14.0)	158	99	91	85	232	201	NR	NR	NR	NR	35	225	173	102	331	27	103	140	108	NR	NR
(Finlayson, Turner et al.	UK	62	18-66: 37.1 (12.8)	62^	0	0	0	27	35	61	0	1	0	2	27	33	51	11	0	16	46	0	NR	NR
(Frey 2004)	USA	22	26-44* : 34.9 (9.0)	22	0	0	0	11	11	NR	NR	NR	NR	3	7*	12	21	1	NR	NR	NR	NR	2	1
(Hawkins and Look 2006)	UK	19	22-25: 38 (NR)	6	6	7	0	16	3	NR	NR	NR	NR	0	19	0	NR	NR	3	6	6	4	NR	NR
(Hilgenkamp, Reis et al.	Netherlands	257	50-81: 59.7 (6.9)†	88	143	10	0	133	124	NR	NR	NR	NR	17	237 †	3	NR	NR	NR	NR	NR	NR	NR	NR
(McGuire, Daly et al. 2007)	Ireland	157	16-65: 37 (11.73)	22	99	20	14	81	74	NR	NR	NR	NR	0^	88	64	NR	NR	3	39*	49	39	NR	NR
(McKeon, Slevin et al. 2013)	Ireland †	17	19-59^: 42 (NR)	6	2	9*	0*	17	0	NR	NR	NR	NR	5	2†	10†	NR	NR	NR	NR	NR	NR	NR	NR
(Peterson, Janz et al. 2008)	USA	131	18-60: 37.2 (11.6)	73	41	0	0	63	68	NR	NR	NR	NR	0	131	0	124	7	NR	NR	NR	NR	NR	NR
(Phillips and Holland 2011)**	UK	152	12-64: 33.6 (14.7)	54	56	42	0	74	78	NR	NR	NR	NR	0	91	61	14	138	3	45	50	54	NR	NR
(Stanish 2004)	Canada	20	19-65: 36.8* (NR)	20	0	0	0	8	12	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
(Stanish and Draheim 2005)	Canada	103	19-65: 37.3 (10.7)	NR	NR	0	0	65	38	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
(Temple 2007)	Canada	37	18-52: NR	NR	NR	NR	NR	18	19	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR

NOTES: Sample size= intellectual disability sample size in the studies; SD = standard deviation; NR= not recorded; *calculated based on data provided; **less than 5% of data is from participants <16years old; ^Inferred but not stated; †data/information obtained from author.

Eleven studies used objective methods, five of which used accelerometers (Barnes et al., 2013; Dixon-Ibarra, Lee and Dugala, 2013; Finlayson, Turner and Granat, 2011; Frey, 2004; McKeon, Slevin and Taggart, 2013; Phillips and Holland, 2011), five used pedometers (Hilgenkamp et al., 2012; Peterson, Janz and Lowe, 2008; Stanish, 2004; Stanish and Draheim, 2005a; Temple, 2007), and one study used both accelerometers and pedometers (Dixon-Ibarra, Lee and Dugala, 2013). Nine studies reported the number of steps/day (Table 2.3) with a mean of 6794.7 (range 5308 to 9632, SD 908.6) steps/day. Overall, only two of the included studies (Finlayson et al., 2009; McGuire, Daly and Smyth, 2007) measured PA in participants with profound ID, and they used semi-structured interview and a questionnaire survey, neither of which was shown to be valid or reliable (see Table 2.1 question 13).

Most of the studies did not record the number of invitees. Consequently, it was difficult to predict recruitment rate. However, one study consisting of people with mild to moderate intellectual disabilities found that 39% of people invited agreed to take part (Peterson, Janz and Lowe, 2008) and two of the studies that used survey/interview found the response rate in people with mild-moderate intellectual disabilities to be above 60% (Finlayson et al., 2009; McGuire, Daly and Smyth, 2007).

2.3.2. PA levels of adults with intellectual disabilities

The studies used different PAG as outcome measures to determine the number of participants classified as 'active' (Table 2.3). PAG were country specific, and some of these were based on frequency and intensity of PA, while others were based on the number of steps/week. The intensity and frequency based PA criterion were essentially a derivative of the 'global PAG for health' (World Health Organisation, 2010), whereas the health-related criterion for the number of steps was those achieving ≥10,000 steps/day (Tudor-Locke et al., 2008). In the majority of the studies, only one PAG was used to determine the percentage of active people. However, three studies (Dixon-Ibarra, Lee and Dugala, 2013; Finlayson, Turner and Granat, 2011; Stanish and Draheim, 2005a) used two different guidelines on the same population. They used intensity or frequency based PA criterion as well as number of steps. There was a difference between the number of participants who achieved equivalent 150 mins MVPA and those achieving ≥10,000 steps/day. Two of the studies found that higher number of participants achieved ≥10,000 steps compared with those that achieved 150 mins MVPA (Stanish and Draheim, 2005a; Finlayson, Turner and Granat, 2011).

Between 0 and 46% achieved 150 mins MVPA, while 7- 45% took ≥10,000 steps/day with an average of 6851 steps/day (range 5308 to 9632). Overall, the number of participants

Table 2.3 Synopsis of included studies on the measurements of PA levels and key findings

Author & year	Sample size	Study design	Inclusion criteria	Measurement tool	PAG	*% meeting PAG*	*Mean steps/d (SD)*	Main results and issues raised in the discussion
Barnes, Howie et al. 2013	131	Cross-Sectional	Aged 18–65 years, have mild to moderate ID, were ambulatory, were not underweight, and did not have any serious medical conditions, were able to comprehend and communicate verbally, and able to give informed consent.	Physical Activity Checklist Interview (PACI) + Accelerometer	150 Mins of MVPA	23.70%	NR	Older individuals had a significant lower MVPA compared with younger adults; males had a significant higher MVPA than females; the most common activity reported was walking (53.7%) followed by inside chores (42.5%).
Dixon-Ibarra, Lee et al. 2013	76	Case control	All participants were verbal, ambulatory, and could recite what they had to do for the study and did not have severe ID	Pedometer and accelerometer	>10,000 steps/day 150 Mins of moderate PA/75 mins of vigorous PA in bouts >10 mins	7.2% * 11.76%*	5452.26* (3024.85*)	A small proportion of older adults with intellectual disabilities (6%) met the national PA guideline and sedentary behaviour was also an observable factor in this study.
Finlayson, Turner et al. 2011	62	Cross-Sectional	Participants were aged 16 and over with mild to moderate intellectual disabilities with capacity to consent.	Semi structured interviews & accelerometer	>10,000 steps/day 30 mins of MVPA for at least 5 days/week	27% 15%	8509 (4384)	Sixty-six percent of participants wore the activity monitor at least 5 days. Mean steps/day was significantly different between men and women (P = 0.001): 11 101 and 6481, respectively.

Frey 2004	48	Case control	Participants were free from physical or sensory conditions; ambulated freely; co-existing morbidity did not limit PA participation or other activities of daily living.	Accelerometer	30 mins of continuous bouts of moderate to very hard activity	0%^	NR	PA levels of adults with mental retardation are similar to those of sedentary peers without. Neither group engages in recommended levels of PA
McKeon, Slevin et al. 2013	17	Cross-Sectional	NR	International PA Questionnaire (IPAQ) + accelerometer	Moderate to high activity 5 days/week^	46%*	5308 (5502)	The average time spent in sedentary behaviour from the accelerometer and an IPAQ (short version) was 10.17 (SD, 2.06) and 9.36 h (SD, 3.21) per day, respectively
Phillips and Holland 2011**	152	Cross-Sectional	Participants were known to intellectual disability services, were aged 12 years and above, and could walk unaided.	Accelerometer and a time sheet	30 mins of MVPA for at least 5 days/week in bouts of 10 mins	0%	6334**	Males were more active than females. There was a trend for PA to decline and sedentary behaviour to increase with age, and for those with more severe levels of intellectual disability to be more sedentary and less physically active.
Hilgenkamp, Reis et al. 2012	257	Cross-Sectional	They were eligible if they found pedometer acceptable and have a comfortable walking speed of 3.2 km/hour or more in at least one of three recordings.	Pedometer and a diary	>10,000 steps/day	16.7%	6600.99* (3519.95*)	The measured sample was the more functionally able part of the total sample; therefore, this result is likely to be a considerable overestimation of the actual PA levels in this population.

Peterson, Janz et al. 2008	131	Cross-Sectional	Ambulatory individuals aged 18−60 years with mild−moderate ID receiving ≥10 h/week of group supported living services; lived outside the family home; able complete interview meaningfully.	Pedometer	>10,000 steps/day	14.10%	6621 (3366)	PA (steps/day) achieved by most of this population is insufficient for health benefits, particularly among individuals with moderate intellectual disability. Evenings and weekends are especially inactive time periods.
Stanish 2004	20	Cross-Sectional	NR	Pedometers	>10,000 steps/day	45%	9631.8*	Week days steps/day in this group are comparable to the wider population. Males and females with mental retardation are a homogenous group in regard to walking activity.
Stanish and Draheim 2005	103	Cross-Sectional	NR	National Health and Nutrition Examination Survey (NHANES) III + Pedometers	>10,000 steps/day Five or more bouts of MVPA/week totalling 30 mins per bout	21.4% 17.5%	7832*	Only 17.5% of the participants reported engaging in five bouts of MVPA/week totalling 30 min per bout.
Temple 2007	37	Cross-Sectional	NR	Pedometers	>10,000 steps/day	Not stated	8100 (3735.4)	The best predictive variables of steps/day were barriers to PA and preference for sedentary behaviour
Emerson 2005	1542	Cross-Sectional	They were eligible if they lived in supported accommodation	PA Scale	12 bouts of MVPA in 4 weeks (retrospectively)	4%	NR	Men and women with ID were less active than men and women without ID in all age groups ($P < 0.001$)

Finlayson, Jackson et al. 2009	433	Prospective longitudinal study	All adults with intellectual disabilities within a defined geographical area were included	Semi structured interviews	30 mins of MVPA for at least 5 days/week	5%	NR	Walking is the commonest regular physical activity, but not at a sufficient intensity level or duration; Older age, immobility, epilepsy, no daytime opportunities, living in congregate care and faecal incontinence were independently predictive of low levels of activity.
Hawkins and Look 2006	19	Cross-Sectional	They were eligible if they could walk unaided	Diary	30 mins of MVPA for at least 5 days/week	11%*	NR	The levels of PA were higher in the sample population than previous figures for adults with learning disabilities, but lower than figures for the wider population.
McGuire, Daly et al. 2007	157	Cross-sectional	Included in the study were carers of adults with an ID – in residential group homes and in the family setting	Lifestyle and Health Behaviour Questionnaire	20 mins of mild exercise four or more times/week***	25.90%	NR	There were no gender differences in health and lifestyle profiles.

who achieved the equivalent of 150 mins MVPA or ≥10,000 steps/day was 9% (weighted average) with a range of 0-46%. For larger studies (those that included 50 participants or more) this range drops to 0-27%.

2.3.3. Factors influencing physical activity levels in adults with intellectual disabilities

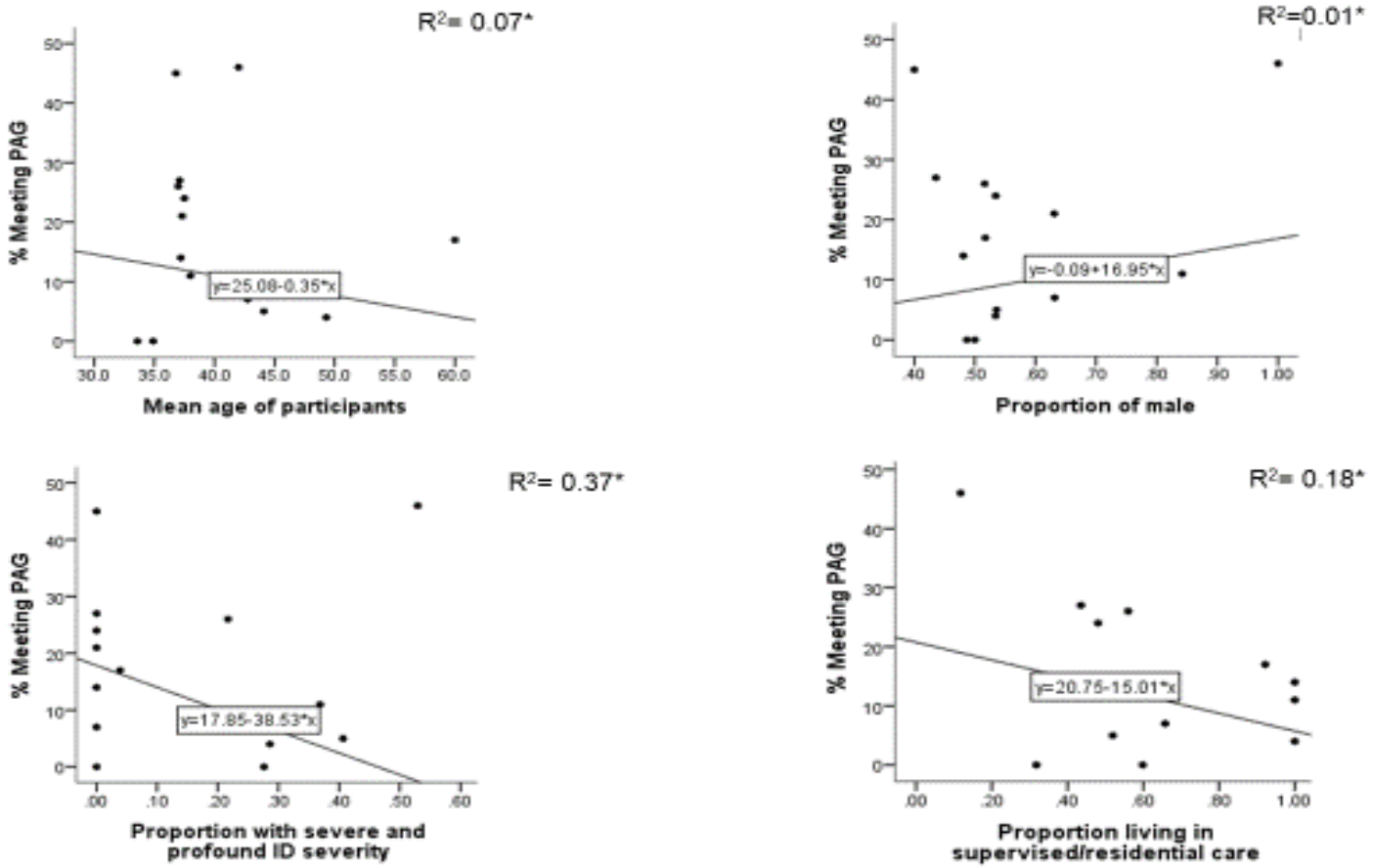
A multiple linear regression analysis revealed a significant linear relationship between the percentage of participants meeting PAG and the predictor variables of age, sex, residence, and IDS. The regression model was highly significant [$F(4, 2994) = 941.17$, $p<0.001$] with an Adjusted R^2 of 0.56 (Table 2.4). On the average percentage of participants predicted to achieve PAG was estimated to be = 0.063 - 0.169 (living in care) + 0.001 (age) +0.368 (sex) – 0.385 (ID severity); where living in care was coded as the proportion of participants living in supervised or residential care, age was measured in years (mean age from each study), sex was coded as the proportion of male, and high IDS was coded as the proportion of participants with severe and profound ID. These results showed that generally 56% of the total variability in the percentage of people meeting PAG was explained by the predictor variables; age, sex, the proportion of people with severe and profound ID, and the proportion of people living in supervised or residential care. The analysis shows that among all predictive variables, the strongest predictor is the proportion of participants with severe and profound intellectual disabilities with a Beta of 0.631 ($t_{(4)} = 49.934$, $p<0.001$). Therefore, a 1 % increase in the proportion of participants with severe and profound intellectual disabilities had a relative contribution of approximately 0.63% of the dependent variable when all the other factors were controlled for. On the other hand, age had the weakest contribution to the regression equation with a Beta 0.101 ($t_{(4)} = 6.354$, $p<0.001$). These results were consistent with the linear regression performed on individual relationships between predictor variables and the percentage of adults with intellectual disabilities who met PAG.

The linear regression showed a significant linear relationship between the percentage of participants meeting PAG and each of the predictor variables; age, sex, residence, and IDS. Each of the regression equation was significant as shown in Figure 2.2. All the relationships were also significant, $p<0.001$ (Figure 2.2).

Table 2.4 Summary of multiple linear regression analysis for the variables predicting the percentage of adults with intellectual disabilities that met PA guidelines (n=2999)

Model Summary**				**ANOVA[b]**			**Coefficients[b]**			
R	R Square	Adjusted R Square	Std. Error of the Estimate	df (regression, residual)	Mean Square (regression, residual)	F		B	Beta	t
.746[a]	.557	.556	.05352	4	2.695	941.168*	(Constant)	.063		5.213*
				2994	.003		Proportion living in supervised/residential care	-.169	-.477	-30.039*
							Mean age of participants	.001	.101	6.354*
							Proportion of male	.368	.232	18.092*
							Proportion with severe and profound disability	-.385	-.631	-49.934*

[a]Predictors: (Constant), mean age of participants, proportion of male, proportion with severe and profound ID severity, proportion living in supervised/residential care
[b]Dependent Variable: % meeting PA guidelines
*significant at p value <0.001
** Using the enter method



Notes: *significant at p value <0.001; ID, intellectual disabilities; PAG, physical activity guidelines

Figure 2.2 Summary of linear regression analysis for the variables predicting the percentage of participants that met PAG (n=2999)

2.4. Discussion and Conclusions

2.4.1. Discussion

The author observed that only nine percent of the participants in the studies achieved an equivalent of the global PAG of 150 mins MVPA. This number that achieved PAG ranged from 0-46%, with two of the studies reporting zero percent (Phillips and Holland, 2011; Frey, 2004). IDS, living in care, gender, and age were independently significantly correlated with the number of participants achieving minimum PAG; the strongest predictor being the IDS. Overall, adults with intellectual disabilities were not as active as the wider population. Given the findings that only nine percent of the participants met PAG, this means that 91% of the participants were not sufficiently active. In 2010, WHO defined insufficient PA as not performing at least 150 minutes of moderate-intensity PA/week (or equivalent), and they estimated that globally, 23% of adults aged 18+ years were insufficiently active (men 20% and women 27%), and older adults were less active than younger adults. Clearly, the percentage of inactive participants in this review is higher than the global healthy population, even though the participants are relatively young adults with an approximate mean (weighted) age of 46 years. Interestingly, for those participants with number of steps/week recorded, they took an average of 6851 steps/day. Although this number of steps/week is within the range of the wider adult population, it falls within the older adult range, the lower end of the range. A meta-analysis by Bohannon (2007) estimated daily adults steps to be within a range of 3,766 to 18,425 steps/day; these were greater in subjects younger than 65 years of age (216–10,377) compared with subjects 65 years of age or older (897–8,233).

A review by Temple, Frey and Stanish (2006) found that 18 - 45% of adults with intellectual disabilities met the health promotion recommendation of 30-mins of moderate intensity PA a day or accrued ≥10,000 steps/day. That range is narrower compared to the 0-46% found in this review. This might be because, as well as methodological differences, most countries had revised their PAG with current guidelines considering continuous bouts of PA as well as overall duration and frequencies of PA/week. Allowing for continuous bouts of PA is likely to reduce the number of participants who are judged to be active.

It is difficult generalising PA levels of the participants in this review to the whole intellectual disabilities population for several reasons. It is likely that they were more active than the general intellectual disabilities population as the data in this review was informed by a sample that was selective and did not appear to represent the intellectual disabilities population. Only 99 out of the 3159 participants were reported as having profound

severity with most of them classified as having mild to moderate IDS. The inclusion criteria also meant that only the very active part of the mild to moderate severities was included. For example, most of the studies excluded people who required walking aids and although there are no available statistics on the number of people with intellectual disabilities requiring walking aids, motor impairment is very common among this group of people (Pratt and Greydanus, 2007; Harris, 2006). This selectivity in sampling was also evident in the fact that nearly half of the participants were reported to be in employment and four of the six studies that reported employment history had more people in work than out of work (Table 2.2), which is in stark contrast to 6.4% of the intellectual disabilities population reported to be in paid employment (Health and Social Care Information Centre, 2011).

There is, however, a chance that the number of participants meeting PAG was underestimated as all the studies that used the number of steps criteria used ≥10,000 steps/ day. Tudor-Locke et al. (2011) found that 150 mins MVPA translated to approximately 7000 steps/day. Consequently, participants who took less than 10,000 but >7000 steps/day who may have been deemed inactive would have achieved 150 mins of MVPA, and so increasing the number meeting PAG. In spite of this, it is more likely that the data from this review is an upward estimate of PA levels in adults with intellectual disabilities because of the relatively low number of participants with severe to profound IDS, and the stringent inclusion criteria.

Predictors of PA levels

The results from the meta-analysis show that higher IDS, living in supervised/ residential care, and older age were independently negatively correlated to the number of participants achieving PAG, while the proportion of males was positively correlated. The individual studies did not always evidence these correlations, and in some instances, the studies reported conflicting results. For example, Finlayson et al. (2009) and Hilgenkamp et al. (2012) found that male participants were more active than females, whereas Stanish (2004) reported the opposite. The latter study was small, consisting of only 20 participants who were all in the mild range of IDS and were younger compared to the other two studies, both of which were of better quality as evidenced by their higher quality scores.

When all the predictive factors were considered, the strongest indicator of PA level was the level of IDS. The higher the proportion of people with severe and profound intellectual disabilities, the lower the number of participants achieving PAG. This finding is important as approximately a quarter (27%) of the sample in this review had severe to profound severities. People with severe or profound intellectual disabilities are characterised

among other things by limited motor functioning (Harris, 2006; Pratt and Greydanus, 2007). This is likely to make PA more difficult than in people with mild to moderate range.

Although age on its own had a negative correlation with PA level, when combined with the other predictor variables in a multiple linear regression, the correlation becomes a positive one, albeit with a very small coefficient of 0.001. This is probably because mean age was used with a relatively narrow range of 33.6 to 59.7 years and without the study by Hilgenkamp et al. (2012), which was primarily in older adults (age range 50-81), this range narrows even further to 33.6 to 49.3years. Another likely reason could have been a multicollinearity effect; however, the multicollinearity test was not statistically significant for the predictor variables.

Implications for future research

The objective PA measures used in this study have been shown to be practicable in adults with intellectual disabilities, but only in participants who are mild to severely disabled, and they are yet to be used on individuals with profound IDS. Future studies could examine the feasibility of using motion sensors such as accelerometers or pedometers in individuals with profound severities. Additionally, future PA research in this population should consider issues of validity and reliability when using subjective PA measures as they may be more applicable in large-scale population studies. Matthews et al. (2011) argue that less resource intensive methods are required for large-scale surveillance. In the wider population, the IPAQ (Craig et al., 2003) is commonly used for surveillance studies worldwide, and some studies (McKeon, Slevin and Taggart, 2013; Matthews et al., 2011) have used it as a PA measure in adults with intellectual disabilities, but its validation studies are inconsistent. Matthews et al. (2011) found that as PA increased above 10 minutes/day, the agreement between accelerometer and IPAQ decreases, while McKeon and colleagues (McKeon, Slevin and Taggart, 2013) reported equivalent results from PA levels obtained from accelerometer and IPAQ. These inconsistencies indicate the need for more research in this area.

Unlike the objective measures that have been demonstrated to be valid among adults with intellectual disabilities with mild to moderate severities (Stanish, 2004; McKeon, Slevin and Taggart, 2013), none of the subjective methods used in this review have been validated in people with intellectual disabilities except IPAQ. Therefore, further research is required to validate these instruments across individuals with different severity levels, especially in those with profound ID.

Finally, apart from the data quality, the scope of PA data would need to be improved and widened so that comparison with the wider population is possible in terms of different age

groups, IDS (mild, moderate, severe, profound), ethnicity, presence or absence of co-morbidities, and presence of CVD risk factors.

2.4.2. Limitations

Risk of bias: Due to time and resource constrictions, only peer reviewed articles published in the English language were included in this review. Although the search strategy did not return any articles published in other languages or unpublished thesis, it is possible that the search filters applied may have excluded such articles. Likewise, no attempt was made to locate unpublished studies and grey literature. Therefore the author cannot rule out publication bias.

Quality of identified research: Intervention studies in adults with intellectual disabilities were excluded. While this reduced the PA data included, the exclusion was applied to limit potential selection bias from intervention studies due to more stringent inclusion criteria.

Reporting bias: Further limitations of this review arise from the included studies' methodological differences, namely sampling method, inclusion criteria, differences in PA measuring instruments, and outcome measures (inconsistencies in the PAG used by different researchers and how they were used). All these factors hampered synthesis of the results, made comparisons between studies difficult and made it difficult to make full use of the extracted data. Meta-analysis was only possible using a simple linear regression as there were insufficient data values for meta-regression and one study was excluded from the meta-analysis due to insufficient data. Also, subgroup analysis was impossible as there were insufficient data for different age groups, IDS, and presence of CVD risk factors such as overweight, cholesterol, and hypertension. This limited any further comparison with the wider population.

2.5. Conclusion

This review has established that adults with intellectual disabilities are inactive and that even in those who are active, their PA is only comparable to lesser active people in the wider population. It also shows that objective measures of PA have been used successfully in adults with intellectual disabilities, but mostly in those with mild to moderate severity, and while subjective measures have been used across all intellectual disabilities

levels, they were likely not to be validated. Lastly, the results indicated that IDS, living in care, gender, and age were independently significantly correlated with the number of participants achieving minimum PAG, the strongest predictor being IDS (Beta 0.631, $p<0.001$). These findings highlight a crucial need to increase PA in this population. To inform measurement and intervention design for improved PA, the author recommends that there is an urgent need for future PA studies in adults with intellectual disabilities population to include all levels including those with severe and profound IDS. Also, future research should include information to enable subgroup analysis, particularly across different ages, sex, and IDS, in order to inform risk factor identification for low PA and develop more targeted PA promotion within intellectual disabilities populations.

Chapter 3 (Study 2). A methodological study investigating the feasibility issues in measuring physical activity levels of adults with intellectual disabilities across the spectrum

3. Summary

In Chapter 2, fifteen studies were included consisting of 3159 adults with intellectual disabilities, aged 16-81 years, 54% male and 46% female. Only nine percent of participants achieved minimum PA guidelines. PA levels were measured using objective and subjective methods. IDS, living in care, gender, and age were independently significantly correlated with the number of participants achieving PA guidelines with the strongest predictor being the IDS (Beta 0.631, $p<0.001$). However, most of those studies excluded individuals with severe and profound intellectual disabilities, and the reason for these exclusions was unclear. Also, no study examined the feasibility of measuring PA of adults with intellectual disabilities across the intellectual disability spectrum. Therefore, the study described in this chapter explored the practicalities of recruiting and measuring adults with intellectual disabilities, including those with severe and profound intellectual disabilities. Each participant and their carer or family were given an accelerometer for seven days to measure their physical activities. After which they completed a questionnaire about their PA over the previous seven days.

3.1. Introduction

In spite of the overwhelming evidence of an active lifestyle benefiting health, well-being, and cognitive functioning (World Health Organisation, 2009; Chief Medical Officer, 2011 ; Wen et al., 2011), adults with intellectual disabilities are relatively inactive (Dairo et al., 2016). As discovered in the previous chapter, compared to the wider population, they have lower-levels of PA. Besides, they take part in PA less regularly (Robertson et al., 2000; Draheim, Williams and McCubbin, 2002; Frey, 2004; Emerson, 2005; McGuire, Daly and Smyth, 2007; Finlayson et al., 2009; Haveman et al., 2011; Dairo et al., 2016). Given the predicted increase in the number of people with intellectual disabilities and the higher health care costs associated with the management of intellectual disabilities (Honeycutt et al., 2004; Doran et al., 2012), as well as the health disparities they experience (Emerson et al., 2014; Krahn, Hammond and Turner, 2006; Heslop et al., 2014), there is an economic argument for identifying those most at risk of physical inactivity. Recognising at-risk groups will not only ensure that resources are targeted appropriately, but will likely

lead to better outcomes at a lower cost. After all, PA benefit is higher for the least active people (World Health Organisation, 2010; Kyu et al., 2016).

PA measures should be applicable across an intellectual disability spectrum (i.e. from mild to profound severities), to identify those who are most at risk of inactivity. However, at present, no validated measure has been used across the range of ID. Individuals with severe or profound severities may have many impairments, including limited motor functioning (Harris, 2006; Pratt and Greydanus, 2007). Consequently, being physically active is likely to be more challenging than in people with mild to moderate range of intellectual disabilities. Furthermore, evidence suggests that the severity of the intellectual disability is the most significant determinant of PA levels (Dairo et al., 2016). Moreover, in the UK, a significant proportion (approximately 30%) of those with intellectual disabilities have severe to profound severity (Gates and Atherton, 2007). Therefore, to inform effective measurement of PA in this group of people, we need measures that can be used on those with mild to moderate, as well as those with severe and profound intellectual disabilities. This is important because although higher levels of PA are significantly associated with lower risk for breast cancer, colon cancer, diabetes, ischaemic heart disease, and ischemic stroke events, the most significant health gains occurred at lower levels of PA (600 metabolic equivalent (MET) minutes/week or 150 minutes of moderate PA or its equivalent per week) (Kyu et al., 2016).

PA can be measured either subjectively or objectively. Subjective methods rely on either recall of PA or a prospective recording of it, while objective methods measure it prospectively over a period. Both approaches have inherent limitations, and they can be challenging to use in adults with intellectual disabilities. In Chapter 2 the author found that several studies have used objective measures such as accelerometers (Frey, 2004; Finlayson, Turner and Granat, 2011; Phillips and Holland, 2011; Barnes et al., 2013; Dixon-Ibarra, Lee and Dugala, 2013; McKeon, Slevin and Taggart, 2013) and pedometers (Hilgenkamp et al., 2012; Peterson, Janz and Lowe, 2008; Stanish, 2004; Stanish and Draheim, 2005a; Temple, 2007), but they were limited to people with milder severity. Furthermore, it was found that subjective PA measures, including diaries (Hawkins and Look, 2006), semi-structured interviews and questionnaires (McKeon, Slevin and Taggart, 2013; Barnes et al., 2013; Stanish and Draheim, 2005b) have been used, yet they were not validated in adults with intellectual disabilities, except for the International Physical Activity Questionnaire (IPAQ[7]) (McKeon, Slevin and Taggart, 2013; Matthews et al., 2011). Though objective measures of PA are accepted to be a more accurate measure

[7] International Physical Activity Questionnaire (IPAQ)

of PA, subjective methods such as the IPAQ may be more applicable in large-scale population studies. The IPAQ is already commonly used for surveillance studies worldwide (Craig et al., 2003), though to the author's knowledge, only two studies have used it as a PA measure in adults with intellectual disabilities . These studies had varied results (McKeon, Slevin and Taggart, 2013; Matthews et al., 2011). Moreover, both study samples were not representative of intellectual disabilities populations as one consisted of only male participants (McKeon, Slevin and Taggart, 2013) and the other, an intervention study, was limited to participants with non-profound severity (Matthews et al., 2011).

From the literature reviewed, no study on intellectual disabilities population has used either the IPAQ or an accelerometer on individuals who are profoundly disabled. In the literature, only one study, Waninge et al. (2013) used an objective method to measure PA levels of people with intellectual disabilities who are profoundly disabled (Waninge et al., 2013). The heart rate patterns of 24 participants (adults and adolescents) were measured continuously using a heart rate monitor for eight hours/day for six days as a measure of their PA level. Even though heart rate as a PA measure in a low active group is problematic because it is also influenced by factors that cause sympathetic reactivity, for example, caffeine consumption, emotional state, and temperature (Strath et al., 2013), the study is nonetheless important. It demonstrates that PA levels can be objectively measured even in individuals with intellectual disabilities who are profoundly disabled. From those studies that used objective methods such as the accelerometer, it is not clear why people with high IDS (severe and profound ID) were often excluded. Moreover, it not known how feasible it is to recruit participants with profound intellectual disabilities or if indeed it is practicable to use objective PA measures with individuals with high IDS.

The feasibility of measuring PA with an accelerometer and with the IPAQ, across the intellectual disabilities spectrum should initially be tested to ensure the appropriateness of the methods of PA measurements (NIHR, 2017). As aforementioned, neither IPAQ-s nor accelerometer have been widely used in adults with profound ID. Therefore, this study will examine the feasibility of measuring PA levels using the short, past 7-day, self/carer-administered form of the International Physical Activity Questionnaire (IPAQ-s[8]) (International Physical Activity Questionnaire, 2002; Craig et al., 2003; Lee et al., 2011) and 7-day accelerometers in a sample of adults with intellectual disabilities consisting of different severity levels. The author hopes that the outcome of this research will influence

[8] short, past 7-day, self/carer-administered form of the International Physical Activity Questionnaire (IPAQ-s)

the design of future PA studies in adults with intellectual disabilities and inform the choice of PA measures in clinical settings, which will thus be valuable for physiotherapists and other professionals involved in promoting or delivering PA intervention and service.

3.1.1. Aims:

To explore the feasibility of measuring PA levels in adults with intellectual disabilities using accelerometers and IPAQ-s, including those with profound ID.

3.1.2. Objectives

- Establish the response rate of individuals with intellectual disabilities who were sent information about the study and an invitation to participate.
- Establish the recruitment rate of individuals with intellectual disabilities who agreed to participate in the study.
- Determine the characteristics of those who were informed, invited and agreed to take part (participants) compared to those who also were informed and invited but did not participate (non-participant intellectual disabilities population).
- Establish the number of participants with accelerometer-derived and IPAQ-s reported PA (min/day) and sedentary time (hours/day).
- Explore acceptability of PA measures by determining compliance with completing the measures.

3.1.3. Research questions

1) What is the response/recruitment rate of those invited to take part?
2) What are the characteristics of those who did take part?
3) Do adults with intellectual disabilities find the PA measures acceptable?

3.2. Methods

This cross-sectional feasibility study was prepared and reported with reference to the 'STROBE -A checklist to Strengthen the Reporting of Observational studies in Epidemiology' (Knottnerus and Tugwell, 2008; Langan et al., 2011). Recruitment and data collection took place between January and June 2016 in Buckinghamshire, a local authority in the UK.

3.2.1. Recruitment

Target population: Adults 18 years and above on the Buckinghamshire local authority's list of individuals with an intellectual disability. There are approximately 1000 adults with intellectual disabilities in Buckinghamshire that are known to the local authority (this consists of people known to GPs, health and education services).

Sampling method: A purposeful sampling method was used to obtain a representative sample across the different age groups, sex, and type of residence (Neyman, 1934). IDS was not considered as data was not available.

Invitation: Two hundred out of approximately 1000 people (every fifth person) on the Buckinghamshire local authority's list of adults with intellectual disabilities were identified and selected purposefully by an administrative staff to have a representative sample covering different age groups, type of residence, and both genders. They were then invited to take part by letter. The letter consisted of a letter of invitation, reply slip, and stamped self-addressed envelope. The invitation letter was designed by the author, a specialist intellectual disabilities physiotherapist, with input from a speech and language therapist and an adult with an intellectual disability. The invitation letter had a summary information about the study (Appendix 2). This is to ensure that the information received by post is not overwhelming and is manageable by individuals with an intellectual disability. The author's contact details were on the invitation letter, and potential participants were asked to make contact either by phone or by returning the reply slip in the self-addressed envelope that was provided.

In addition to the invitation letter; to increase representation from those invited with severe and profound intellectual disabilities, there were presentations by the author to invitees in residential-homes, intellectual disabilities service events, and at day centres, and recruitment emails were sent to care providers of residential-homes of invitees. Additionally, reminder emails were sent to the residential-homes every four weeks until a response was received. In instances where none of the invitees from a residential-home responded, or the home responded on behalf of potential participants, declining the invitation, the author phoned them to find out reasons for non-participation.

3.2.2. Screening and eligibility

People who indicated an interest in participating were contacted by phone or e-mail to address any further questions and to screen them for suitability to participate using the eligibility criteria below:

3.2.2a. Inclusion criteria

- Participants aged 18 years and above;
- Reside in Buckinghamshire;
- ID diagnosed using any recognised diagnostic criteria or identified as having intellectual disabilities by the social services department or using the specialist intellectual disabilities service or had done so in the past.

3.2.2b. Exclusion criteria

- People or carers who do not understand instructions in English;
- Individuals who are not able to communicate consistently and effectively with people that they are familiar with (communication can be verbal, written, use of body language or with augmentative and alternative communication devices);
- Acute musculoskeletal injury, such as fractured limb, sprains and strains;
- Individuals with a recent history (last one year) of physical violence or self-injurious behaviour;
- Individuals not able to tolerate wearing the accelerometer, for instance, someone with a history of hypersensitivity to a wristwatch or bracelet;
- Acquired brain (diagnosed in adulthood)/ spinal cord injuries.

3.2.3. Procedure overview

For eligible participants, the author obtained a verbal consent to a home visit. During the home visit, eligible participants and their carers/relatives received written information about the study and a consent form (Appendix 3). All written documents had easy to read sections including illustrative images where possible. Consent was obtained according to the research procedures of the UK Mental Capacity Act (MCA[9]) (UK government Department of Health, 2005). For consenting participants, the author obtained baseline information and explained the procedures for the measurement of their PA levels. Participants and their carers or relatives were given the PA instruments (accelerometers and IPAQ-s). They also received information and instructions on how to wear the accelerometer and how they or their carers would fill in the PA questionnaire. Finally, they received a stamped self-addressed envelope for the return of the accelerometer and the questionnaire.

[9] Mental Capacity Act (MCA)

3.2.4. Data collection

Information on age range, sex, and type of residence was obtained from social care records of all invitees for descriptive purposes and to examine the difference between participants and non-participants. For participants, the author obtained consent as described in section 3.2.8. Additionally, information was collected on their age, race, employment status, and level of mobility. The author then assessed: 1) the IDS (see section 3.2.4.1); 2) Body Mass Index (BMI[10]) as described in section 3.2.4.2., and 3) their PA as described in section 3.2.4.3.

3.2.4.1. Level of intellectual disability

The author assessed the IDS by administering the Leicestershire Intellectual Disability tool (LIDT[11]) to the participants or their carer/relative. The LIDT tool was chosen for pragmatic reasons. The other commonly used tests are the Adaptive Behaviour Assessment System (Harrison and Oakland, 2003) and the Vineland Adaptive Behaviour Scale (de Bildt et al., 2005), both of which require specialised training to administer. The LIDT combines seven questions on writing, dressing, speech, preparing food, feeding, empathy, and use of amenities (Tyrer et al., 2008). The tool has a reported diagnostic accuracy of 91% as compared to the Vineland Adaptive Behaviour Scale (de Bildt et al., 2005). Intellectual disabilities level was categorised by the total score of the tool based on the ICD-10 criteria for mild, moderate, severe, and profound severities (Tyrer et al., 2008).

3.2.4.2. BMI classification

BMI was calculated as weight/height^2 (World Health Organisation, 2006), Both weight and height were measured according to standard operating procedures. Weight was measured to the nearest 0.1 kg with the participant dressed in lightweight clothing and barefooted using a calibrated electronic scale (Seca digital floor weighing scale). Height was measured to the nearest 0.5 cm using a portable stadiometer (the Harpenden Stadiometer). BMI was transferred into age and gender appropriate cut-offs for underweight, normal weight, overweight, or obese (World Health Organisation, 2006).

3.2.4.3. Physical activity assessment

The participant and their carer/relative received an accelerometer during one home visit by the author in their homes. The primary outcome data from the accelerometer is a recording of body acceleration and deceleration which can be expressed as PA count per seconds/hours (Strath et al., 2013). The accelerometer models used were Axivity AX3 version V1.2 (Axivity 2013) or GENEActiv version 2.9 (ActivInsights Ltd 2013). They were shown how to wear the accelerometer on their wrist (left or right depending on preference)

[10] Body Mass Index (BMI)
[11] Leicestershire Intellectual Disability tool (LIDT)

during all waking hours for seven consecutive days, with instructions on how to contact the author in case of discomfort or equipment malfunction. The participants also received copies of the IPAQ-s (International Physical Activity Questionnaire, 2002; Craig et al., 2003; Lee et al., 2011), in which pictures of PA and time were included, for ease of understanding (Appendix 4). They were instructed that on the 8th day, they and or their carers would complete the questionnaire and return it with the accelerometer in a stamped self-addressed envelope. Neither of the PA instruments contained participants' identifiable information.

Accelerometers

Accelerometers have the advantage of capturing frequency, duration, and intensity of physical movement in a time-stamped manner (Strath et al., 2013). They can record high-resolution data, as well as store data for several days to weeks depending on the model of the accelerometer and the frequency of measurement. The device is usually enclosed in a case and can be strapped to various parts of the body, including the hip, ankle, wrist, or lower back. More recently, wrist-strapped ones are commonly used as they are easier to apply than, for example, the waist-mounted accelerometers, which fail to detect arm movements (Chen and Bassett, 2005). The wrist-strapped accelerometers have excellent criterion validity (Esliger et al., 2011) and an accurate intensity classification across a broad range of activities (Welch et al., 2013; Esliger et al., 2011).

Accelerometry validation studies suggest a relatively high degree of validity for quantifying the intensity of PA levels (Kozey-Keadle et al., 2011; Esliger et al., 2011; Freedson, Melanson and Sirard, 1998; Hale, Pal and Becker, 2008; Tweedy and Trost, 2005). These studies were performed in controlled laboratory settings in several groups of subjects (including participants with acquired brain injury), as well as during free-living conditions. In addition, average intensity (counts per minute) measured over several days has been shown to be significantly associated with energy expenditure estimates measured by the doubly labelled water method under free-living conditions across different age groups (children, adolescents, and adults) (Ekelund et al., 2001; Ekelund, Aman and Westerterp, 2003; Leenders et al., 2001).

The technical specifications of the accelerometer monitors used in this study are described in the SOP (Appendix 5). Briefly, accelerations ranging in magnitude from 2.0 to 8.0 g are measured by sensors (micro electro---mechanical system), sampled at 25 Hz, and then summed over 60 seconds time interval (epoch). As explained in section 3.3 (results), two types of monitors were used – Axivity and GENEActiv. Both are triaxial

accelerometer measuring accelerations in all three planes of motion. The monitors are in a case and attached by straps like a wristwatch. They are lightweight (Axivity is 12g and GENEActiv 16g) and provide detailed information about the intensity, frequency and duration of PA with sufficient storage capacity for monitoring PA minute-by-minute for up to 3 weeks.

International PA Questionnaire

The International PA Questionnaire (IPAQ), in its long-form, provides a comprehensive measure of activity in a variety of contexts (occupational, transportation, household, leisure) and intensity domains (sitting, moderate, vigorous, walking, cycling) (Craig et al., 2003). The IPAQ was adapted into a short-version (IPAQ-s) initially for use with older adults, but has since been used in specialist population like the intellectual disabilities population (Matthews et al., 2011; McKeon, Slevin and Taggart, 2013). The IPAQ-s is a short recall PA questionnaire that provides a quick assessment of the total volume of PA classified by the dimension of intensity level or by domain (Strath et al., 2013). The IPAQ-s asks about three specific types of activity undertaken in the same domains as the long form (i.e. occupational, transportation, household, leisure). The activities assessed by IPAQ-s are walking, moderate-intensity activities and vigorous-intensity activities (www.ipaq.ki.se., 2005).

The IPAQ-s questionnaire is based on a recall over the last seven days. It is easy to use, does not require specialised training, and can be downloaded for use from the IPAQ website (www.ipaq.ki.se). Types of activities surveyed are like the long form, including moderate- and vigorous-intensity categories, walking, and sitting. It has seven questions and can be self/proxy- or interviewer-administered face-to-face or over the telephone. It can be used to collect continuous data in MET.min per week or PA mins/week and categorical scores (Lee et al., 2011; Craig et al., 2003), but the PA mins/week is the most used. The IPAQ has been used with different populations, including adults, men, women, older adults, white, Chinese, Japanese, Latino, Hispanic, and black (Strath et al., 2013). It has excellent test-retest reliability (Silsbury, Goldsmith and Rushton, 2015) and acceptable criterion validity (Craig et al., 2003; Silsbury, Goldsmith and Rushton, 2015).

3.2.5. Study size

For a feasibility study, sample sizes between 24 (Julious, 2005) and 30 (Browne, 1995; Lancaster, Dodd and Williamson, 2004), have been recommended. In addition to those sample size recommendations, the author considered the statistical test for the data analysis. In the Chi-Square goodness of fit test, sample data is divided into categories. Then the numbers of points that fall into each category (observed) are compared, with the

expected numbers in each category. The minimum expected cell frequency is 5.0 (McDonald, 2014b). Since the highest number of categories in this study is the age group, which has four categories, then the minimum number of participants necessary will be 20. Most PA levels studies in adults with intellectual disabilities do not record the number of invitees (Dairo et al., 2016). As a result of which it is difficult to predict the recruitment rate. In the few studies that recorded their recruitment rates, they had direct contact with invitees, unlike in the present study. Those studies reported recruitment rates between 39% and 60% (Finlayson et al., 2009; McGuire, Daly and Smyth, 2007; Peterson, Janz and Lowe, 2008). A study in the older adult population that used similar recruitment strategy to this study, i.e., sending letters to invitees from a mail list, reported a recruitment rate of 13.6% (Jancey et al., 2006). Therefore, the author estimated that to recruit between 20 to 30 participants, 200 out of the approximately 1000 adults on the Buckinghamshire local authority's list (every 5th person to get a good spread) will be invited by letter.

3.2.6. Variables

Independent variables: Age, sex, level of disability, race, type of residence, BMI, level of mobility and employment history.

Dependent variable: Percentage meeting PAG

Feasibility outcome

- Response rate of adults with intellectual disabilities
- Recruitment rate of adults with intellectual disabilities
- Number of participants with complete accelerometer data
- Number of participants with complete IPAQ-s data

Secondary outcome

- Differences between participants and non-participants

3.2.7. Data analysis

Data from Axivity and GENEActiv accelerometers were downloaded directly onto a laptop using software from https://github.com/digitalinteraction/openmovement/blob/master/Downloads/AX3/AX3-GUI-29-beta.zip, and from http://www.geneactiv.org/resources-support/downloads-software/ respectively. The same software also converted the Axivity data, but the GENEActiv data were converted using an in-house custom written program into how much time a participant spends in sedentary, light, moderate- or vigorous-intensity PA

(MVPA[12]) using the left wrist PA cut-points of the Eslinger study (Esliger et al., 2011) - sedentary (<217 counts/min), light (217-644 counts/min), moderate (645-1810 counts/min), or vigorous (>1810 counts/min). Previous intellectual disabilities studies used similar cut-points (Dixon-Ibarra, Lee and Dugala, 2013; Phillips and Holland, 2011). As this was a feasibility study, all accelerometer data were included in the descriptive analysis. In case of monitor failure or lack of data, participants were asked to re-wear the accelerometer for a further one week, where appropriate.

For the IPAQ-s, where participant's daily sedentary hour's data are missing, the participant or their carer/relative was contacted by telephone to supply the data. Detailed analysis of the PA and sedentary behaviour data are provided in Chapter 4.

Descriptive and frequency statistics were used to summarise the characteristics of participants compared to non-participants. A non-parametric statistic, the chi-square goodness-of-fit test was used to determine whether the distribution of participants in the categorical variable age groups (18-29; 30-44; 45-59, 60+), type of residence (living at home or in a residential-care), race (White, Black, Asian, Others) and sex, consisting of two groups: 'participants' and 'non-participants' follows a known or hypothesised distribution. The proportion of participants expected in each group of the categorical variable can be equal or unequal. The number of participants with a completed PA data was analysed using frequency statistics.

3.2.8. Ethical considerations and consent procedures

Ethical approval (Appendix 6) was sought from and granted by the University Research Ethics Committee (no. 150967). The study was conducted in line with the declaration of Helsinki. Capacity was assessed as detailed below in section 3.2.9 and consent obtained according to the research procedures of the MCA (UK government Department of Health, 2005). Participants were provided with space and time in their own home to consent to participate in the study and consent obtained primarily, from each participant. Where a person could not consent, in line with the MCA (UK government Department of Health, 2005), a proxy decision-maker (staff /carer or next of kin) was identified, who must have known the participant for at least six months.

3.2.9. Capacity assessment

'Capacity' is the ability to use and understand information to decide, and communicate any decision made. All adults are presumed to have sufficient capacity to make decisions unless there is significant evidence to suggest otherwise (NHS Choices, 2015). The legal

[12] moderate- or vigorous-intensity physical activity (MVPA)

assumption is that for everyone, we must presume capacity for decision-making until proven otherwise (UK government Department of Health, 2005). As capacity can sometimes change over time, it should be assessed at the time that consent is required, and it should be carried out by appropriately trained and experienced health professionals or researchers (UK government Department of Health, 2005). For the current study, the capacity assessment was carried out by the author, a chartered physiotherapist with considerable experience of working with persons who may not have capacity due to impairment or disturbance in the functioning of the person's mind or brain. Also, the author received training in taking consent and attended the Good Clinical Practice training at Oxford Brookes University.

The author carried out a capacity assessment by checking: that the individual understood the information that they received; they retained the information; they considered the consequences of taking part; and could communicate their decision by talking, writing, using sign language or by any other means. This was done in line with the MCA (2005). Individuals who met the conditions were deemed to have the capacity, therefore, able to consent to participate in the research. However, if any, of the conditions, are not met, a proxy decision-maker (staff /carer or next of kin) was identified, who must have known the participant for at least six months, and able to carefully consider what is in their best interests before deciding about their participation in the study. There are many things to consider in trying to decide what are in a person's best interests. Some of those factors are involving the person in the decision as much as possible, trying to identify any issues they would consider if they were making the decision themselves, including religious or moral beliefs. These would be based on views the person expressed previously, as well as any insight their advocate can offer (UK government Department of Health, 2005; NHS Choices, 2015).

3.3. Results

3.3.1. Response and recruitment rates

A flowchart of the recruitment process was reported (Figure 3.1). Out of 200 individuals invited, 26 (13%) responded to the study invitation of which 23 (11.5%) expressed an interest in taking part, of whom one refused to consent because she did not like the accelerometer – despite having agreed to a home visit. Eventually, 20 (10%) participants were recruited. The recruitment flow is presented in Figure 3.1. On average, residential-homes were sent four reminder emails (range 2-6) and an average of 8 emails (range 4-16) for screening and eligibility. Two out of the eight residential-homes took part with 7out

of 9 individuals that the author had access to agreeing to participate. Table 3.1 summarises the responses and recruitment rate as well as demographics of participants compared to the non-participants.

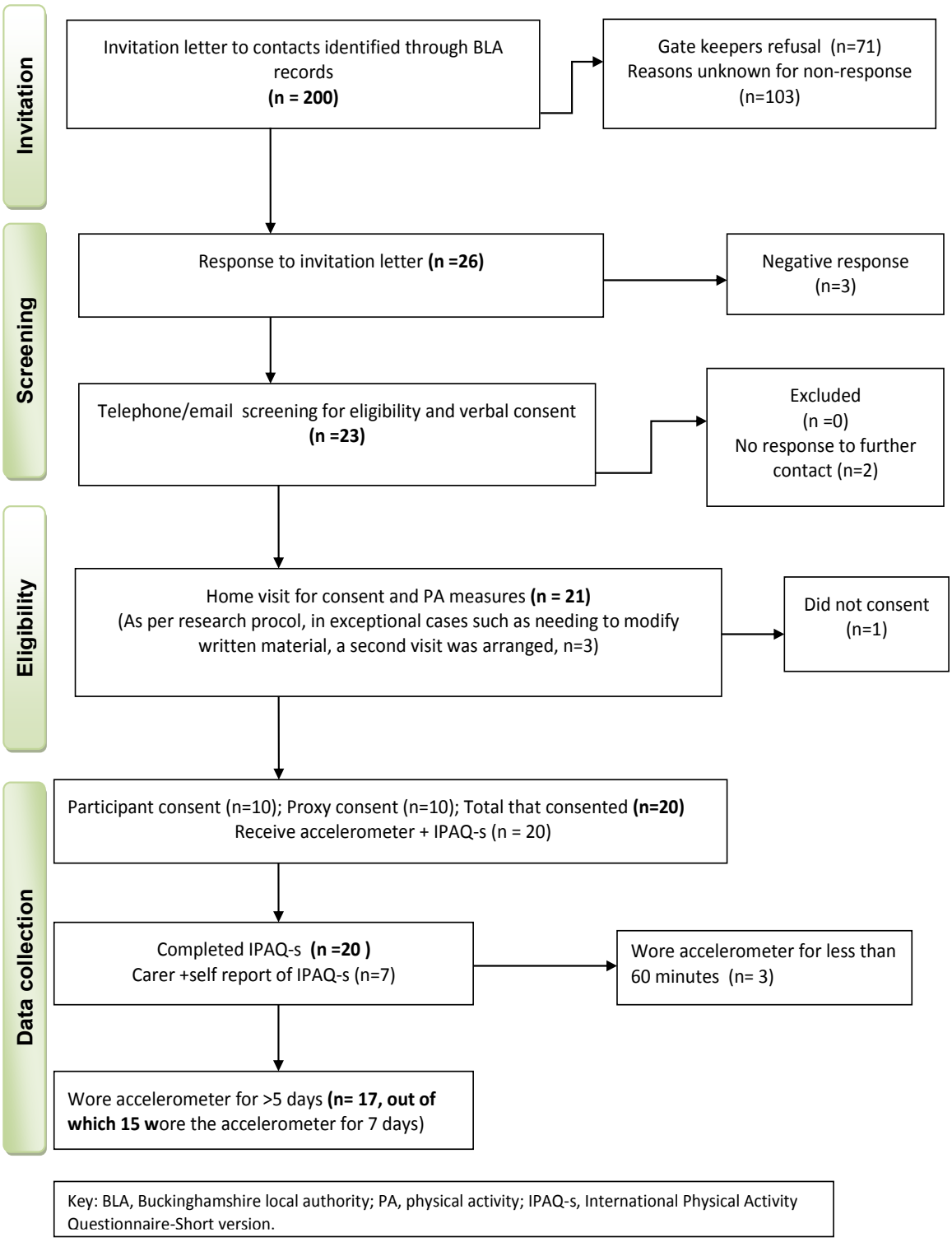


Figure 3.1 Study flow diagram

For the homes where none of those invited took part, five out of six managers said that the burden of wearing the accelerometer for seven days would be too high for the people they support, most of whom might be unable to express their wishes. They also said they would be unwilling to act as proxy respondents for the same reason. Below are responses from the managers (some responses are from the same individual). Each quote is assigned a number from M1- 6 indicating the responses from the six managers.

> *"Some of our residents have a history of aggression, and we are not sure how they will react if you ask them to wear the accelerometer – they can't even tolerate wearing a wristwatch." M1*
>
> *“Most of our residents have profound intellectual disabilities and are non-verbal. How would we explain the research to them?” M2*
>
> *"I don't feel comfortable consenting for someone who is nonverbal." M3*
>
> *"If you are asking them to wear it for one day, it might be okay, but seven days is a lot to ask for especially for our clients who are profoundly disabled." M1*
>
> *"I really don't see how you would get someone like Ms XX to wear this (pointing to an accelerometer) for seven-day unless she can hang it around her neck. Even that is doubtful." M4*

Additionally, the managers cited time pressure created by staff taking the time to read and understand research documents, understaffing due to relatively high staff turnover, and reluctance to spend time on the research paperwork as further reasons for non-participation. What follows are statements by managers.

> *"We can't deal with the research paperwork on top of everything else that we must get ready for CQC. We fill so much paperwork now – sorry." Manager 1*
>
> *"We are understaffed and have to rely on agency workers. We are recruiting over the coming weeks. If you contact me in three months, we might be able to help." M5*
>
> *"Our homes have just been taken over by a new company, and so we are going through a lot of changes now." M5*

One home had mostly clients with mental health issues some of whom has a recent history of physical aggression and another manager was newly appointed to post, and he did not know the residents that well. He said:

"Your research sounds very interesting, and it's something that I would consider for our residents, but I'm newly appointed, and I'm afraid I don't know the residents well enough to be willing to ask you to visit for recruitment. I will need time to settle in. You may contact me again in six months' time." M6

Another reason that was given for non-participation was the mode of invitation. The manager asked the author to invite participants face-to-face as opposed to sending letters. She said:

"It might be better for you to visit rather than sending letters by post." M2

Response Rate

A chi-square goodness-of-fit test was computed to determine whether respondents to the study invitation followed a known distribution using categorical variables: age groups (18-29; 30-44; 45-59, 60+), type of residence (living at home or in a residential-care), race (White, Black, Asian, Others) and sex (Table 3.1). Based on the study's recruitment method, and Buckinghamshire's higher proportion of people living in residential-homes (supported living accommodation or registered care) than the national average, the author anticipated an 'unequal' proportion of participants living at home and in residential-home participating in this study. Therefore, the chi-square goodness-of-fit test was calculated as an expected 62% of participants residing in a residential-home and 38% living at home. For sex and age groups an equal distribution was expected.

There is a statistically significant difference in the response rates of those invited based on where they live, with a less proportion of invitees from "residential-home" responding to the study invitation compared to the percentage of those living at "home". Thus, the response rate for those living in a residential-home was significantly lower compared to those living at home ($\chi 2$ (1) = 7.66, p <. 01 (Table 3.1).

The difference in the response rate among male and female was not statistically significant, as an almost equal number of male and female responded to the study invitation as shown in Table 3.1. Information on the age group of those that responded to the study invitation was not known. Consequently, no statistical inference was made.

Recruitment Rate

Like the response rates above, a chi-square goodness-of-fit test was computed to determine whether participants that consented to participate in the study over the recruitment period of six months, followed a known distribution: 62% of participants living in a residential-home and 38% living at home; equal distribution across age groups; and an equal number of male and female participants. There is no statistically significant difference in the number of participants living at home and those living in residential-homes, $\chi 2$ (1) = 1.22, p =.27. Likewise, there are no statistically significant differences in the number of recruits across the different age groups nor was there a statistically significant difference between the number of males and females that were recruited.

Table 3.1 Demographics summary of participants and their response and recruitment rates

	Age groups				Type of residence		Sex	
Descriptor	18-29	30-44	45-59	60+	Lives at home[a]	Residential-home[b]	Male	Female
Invited, n (%)	50 (25)	50 (25)	50 (25)	50 (25)	76 (38)	124 (62)	100 (50)	100 (50)
Response rate, n (%)	U	U	U	U	12 (16)*	5 (4)*	8 (8)	9 (9)
Home visits, n	3	5	6	7	10	11[c]	10	11
Recruitment rate, n (%)	3 (6)	4 (8)	6 (12)	7 (14)	10 (13)	10 (8)	10 (10)	10 (10)

Notes:
U (information was not available as the Buckinghamshire local authority's list contained age group, but not the actual age); response rate (those that responded to the study invitation over the recruitment period of six months); recruitment rate (those that consented to participate in the study over the recruitment period of six months).
[a]Lives at home with family/alone.
[b]Residential-homes (this includes registered care homes and supported living accommodation).
[c]Interested individuals increased from an initial 5 to 11 following presentations at residential-homes by the author.
*Significant difference between those living at home and those living in a residential-home (p<0.05).

3.3.2. Characteristics of participants

Participants were 20 adults with mild to profound IDS, aged 22 - 70 years, with a mean age of 50 (16) years. All participants were white. The sample had an equal number of male and females (10 males and 10 females), and there was no significant difference in the number of participants recruited from the different age groups, but there was a trend for the recruitment rate to increase as age increased. A detailed summary of participants' characteristics is found in Table 3.2.

Table 3.2 Summary of participants' demographic data, n=20

		Frequency	Percent
Sex	Female	10	50.0
	Male	10	50.0
Race	White	20	100.0
Residence	Alone	2	10.0
	With family	8	40.0
	Registered care	8	40.0
	Supported living	2	10.0
Level of Intellectual Disability	Mild	4	20.0
	Moderate	4	20.0
	Profound	5	25.0
	Severe	7	35.0
Employment	No	19	95.0
	Yes	1	5.0
Mobility	Assistance	2	10.0
	Independent	18	90.0
Mobility Aids	Walker	1	5.0
	Nil	17	85.0
	Wheelchair for >15 mins walk	1	5.0
	Walking Stick	1	5.0

3.3.3. Acceptability of PA measures

All the 20 participants completed the IPAQ-s while for the accelerometer; only 15 participants had a complete seven days data, and two with more than five days, but less than seven days of data. Those two participants with incomplete accelerometer data were both males and lived in residential-homes. One took it off on the 6th day because of a

reported adverse reaction to the accelerometer strap, while the other took it off on several occasions without giving any reasons for doing so. Therefore, their accelerometer data were excluded from the comparative analysis.

All the participants living at home (with family or alone), completed seven days accelerometer data even though their severities ranged from mild to profound. In contrast, the three participants without accelerometer data all lived in a residential-home; all with high severities (two with profound and one with severe intellectual disabilities); wore the accelerometer for less than an hour each; and they were two females and one male. Reasons for not wearing the accelerometer included statements from participants of: “too heavy”, “uncomfortable”, while one participant was ‘fiddling’ with it so much, hence, the author deemed it unsuitable for this participant.

Overall, there were two cases of reported ‘adverse reaction' to the Axivity, due to irritation caused by the strap. Consequently, the sensors were changed to GENEActiv. Therefore, 8 out of 17 received Axivity while the rest (9 participants) received the GENEActiv.

For the sedentary behaviour data, initially, 18 out of 20 participants provided their sedentary hours IPAQ-s data. Those two participants with missing data were followed up by phone to obtain the values from their proxies. As a result, all 20 participants had IPAQ-s sedentary hours data. On the other hand, only 17 participants had accelerometer data (15 with complete data and the other two with more than five-day data).

3.3.4. Ease of physical activity measure

Fourteen out of the 20 participants could recall the duration of their PA classified by the dimension of intensity (i.e. whether moderate or vigorous) over the previous seven days. They could also recall how long they walked for over the same period, but only three of them could estimate their average sedentary hours/day despite prompts (all three had a mild ID). All 20 participants had a completed IPAQ-s data, although, for two of the participants, sedentary behaviour data were obtained by a follow-up phone call to their proxy. It is worth noting that the two participants that were followed up to obtain sedentary hours were both living in a residential-home. Their carers had to be assured that an estimate of sedentary hours was acceptable as they were reluctant to put a number to it in case they got it wrong.

With reference to accelerometers, out of the 17 participants with accelerometer data, most of them (16/17) could wear and remove the accelerometer either independently or with assistance with only one participant reliant on support to wear and take it off.

3.4. Discussion and Conclusions

3.4.1. Discussion

There was a significant difference in the response rates between homes (16%) and residential-homes (4%), and overall low recruitment rates. The author experienced greater difficulty in recruiting people from residential-homes compared to those living at home, which is important for understanding the lack of data on individuals with profound intellectual disabilities. Also, it was found that care home managers were reluctant to allow participation in the study. However, it was possible to measure PA in adults with intellectual disabilities using accelerometers and the IPAQ-s including in those individuals with profound intellectual disabilities. Though, there was a difference in how adults with intellectual disabilities accepted the two PA measures. All the participants completed the IPAQ-s either independently or with the support of their proxy. On the contrary, only 15 participants had a complete 7-day accelerometer data, suggesting that the choice of PA is an important factor for research participation in this population. Additionally, the only participant to refuse to consent after initially signalling interest in the study refused based on their dislike of the accelerometer.

3.4.1.1. Research engagement

A mere 5 out of 124 invitees living in residential-homes initially responded to the study invitation, with only two positive responses. The reasons for this are not fully understood, but the results suggest the reluctance of carers to give consent by proxy could be a contributing factor. Evidence of proxy respondent's willingness in intellectual disabilities population is limited, but studies in other spheres, such as end of life care, found that proxy-decision makers may be left in a stressful and uncomfortable position, where they feel the responsibility of making decisions for someone they support (Arora, Cummings and Crome, 2016). Similarly, an older adult study found that informal caregivers were reluctant to proxy response, especially if they consider the risk to be high (Dubois et al., 2011). These factors might have contributed to carers deciding to exclude individuals from research studies without consulting or involving the person concerned.

The reluctance of managers to allow their residents to participate in PA measurement research is disappointing but not surprising. Research evidence suggests that exposure to the media changes people's behaviour or beliefs (Livingstone, 1996). In recent years in the UK, there has been negative media coverage on the quality and standards of care for adults with intellectual disabilities. For example, a BBC Panorama programme in 2011, showed some staff at the Winterbourne View Hospital (a hospital for adults with intellectual disabilities) physically abusing patients as well as instances of bullying. It

caused outrage among the public, and it generated a lot of public conversations. These open discussions can affect the way the society views people with adults with intellectual disabilities. The perceptions that adults with intellectual disabilities are largely incompetent and in need of protection may lead to unnecessarily restrictive and unjust conditions, including those that those that limit their self-determination (McDonald and Keys, 2008). It is possible that the managers were only trying to protect their residents, but with an unintended consequence of limiting research participation. The perceptions that adults with intellectual disabilities need protection might also explain the 16% response rate for those living at home. It is important that safeguarding and caring responsibilities are balanced with an individual's rights, including their rights to research participation.

The managers also raised issues around staffing and time pressure, but it is likely concerns are heightened by the managers not been involved in the study design. Future studies should try to engage gatekeepers, as far as it is reasonably practicable, in the research design. Some education on balancing safeguarding of vulnerable residents and supporting research participation might also help the managers in their decision-making with regards to their gatekeeper role.

Furthermore, the author would advocate for a research strategy for providers of intellectual disabilities residential-homes so that there is a requirement for providers to create an environment where participation and engagement in research by people with intellectual disabilities can flourish, irrespective of their level of disability. This may necessitate changes to the current ethical application procedure and committees, either for them to have representation from the boards of residential facilities providers or for researchers to be able to apply and have permission granted by a board of all residential facilities. An example of a board of residential services giving permission was found in a recent study that used diaries as PA measures in individuals with profound intellectual disabilities from the Netherlands (van der Putten et al., 2016). As far as the author is aware, that study is one of two, to measure PA consisting of only participants with profound ID. The other study was also carried out in the Netherlands, and although the ethical procedures were not as clearly stated, they were both similar (Waninge et al., 2013; van der Putten et al., 2016). It is hoped that reviewing the current ethical procedures in this population will improve research engagement by people with intellectual disabilities who may otherwise not have the opportunity, especially as gatekeepers often turn down a research invitation without consulting or engaging the individual in question. Such a review could also be of benefit to ethics committee themselves who have been found to create situations that limit the self-determination of adults with intellectual disabilities and

adults without disabilities within the research context, especially, when the research poses some risk of harm to participants (McDonald and Keys, 2008).

3.4.1.2. Demography

This study shows that the type of residence is a key factor in determining response and eventual recruitment rate. For those that responded to the study invitation, the initial response rate was highest among individuals living at home with family and least in those who are living in residential-homes, with half of the recruited participants living at home, even though they made up just a little more than a third of the those invited (Table 3.1). Although age was not significantly different between participants and non-participants, in this feasibility study, the trend was an increasing number of participants with increasing age. This warrants further investigation with an appropriately powered study. It is also likely that race is a factor as all the participants were white. Although there was no information on the ethnic groups of all the invitees, information from the local authority suggests that invitees have different ethnicities with approximately 12% -18% of the Buckinghamshire intellectual disabilities population from Asian origins (MacDonnell, 2014). Therefore, ethnicity may also be a factor affecting recruitment that warrants further investigation.

Few PA levels studies in adults with intellectual disabilities recorded the number of invitees and respondents. One of such study was in individuals with mild to moderate intellectual disabilities in supported living services, with 39% of invitees taking part (Peterson, Janz and Lowe, 2008), much higher than the overall response of 13% found in the current study. Importantly, they had direct access to the participants, in contrast to this study where access to participants was negotiated via 'gatekeepers'. This might have helped their recruitment rate, in addition to the fact that their participants were in the mild-moderate range of IDS. The other studies (Finlayson et al., 2009; McGuire, Daly and Smyth, 2007) to have reported recruitment rates were survey or interview studies and they found the response rate in people with mild-moderate intellectual disabilities to be above 60%. One of the studies (McGuire, Daly and Smyth, 2007) had ethical approval from a local organisation that provides services for people with intellectual disabilities. Therefore, they had direct access to people with intellectual disabilities and their carers, both in the residential setting and in the family setting. In the other study (Finlayson et al., 2009), family physicians were incentivised to identify adults with intellectual disabilities, who were registered with them, and all the identified adults with intellectual disabilities were invited with no exclusions. As discussed later in section 3.4.2, the exclusion criteria may have affected demographics as well as the recruitment rate.

Despite purposefully targeting and committing most of the recruitment efforts into those living in residential-homes, only half of the recruits were from there. In Chapter 2, Study 1 shows that residing in residential-home increases the risk of inactivity. Notably, the local authority area where participants were recruited from has a higher proportion of people with intellectual disabilities living in registered-care than the national average (MacDonnell, 2014).

3.4.2. Strengths and Limitations

This feasibility study showed for the first time that PA could be measured effectively using both subjective and objective methods among adults with intellectual disabilities including in those with profound intellectual disabilities. As can be expected, this study has several limitations as well as strengths. The invitation to the study was by writing to participants selected from a known list (BLA list of adults with intellectual disabilities). While this provides a means of obtaining a representative sample, it provided just the addresses of potential participants, leaving letters as the only viable means of contact. This can be challenging as most people with intellectual disabilities may not be able to read. However, other recruitment methods were considered, such as advertising, but it is problematic for the study aims and use in this population. Advertising for study participants does not allow sampling from a known population. Additionally, community advertisements must be seen by the intended audience and require active participation (Westling et al., 2011). For these reasons, studies that have used advertisement tended to be limited to individuals that have mild intellectual disabilities and can read. Additionally, the author is more interested in obtaining a representative sample than the study power and evidence suggests that direct mail from existing list offers one of the most effective ways of obtaining a representative sample (Westling et al., 2011).

Also, the main aim of this study was to investigate the feasibility of measuring PA levels in adults with intellectual disabilities, including those that are profoundly disabled; therefore, the exclusion criteria were for pragmatic and safety reasons. Hopefully, the number of potential participants excluded would have been minimised. Although the exclusion criteria which was part of the study's invitation letter excluded individuals where either they or their carers or relatives were not fluent in the English language (due to time and resource constrictions), none of the contacts from the research invitation raised any issues relating to language.

3.4.3. Implications for future research

1. Choice of PA measure

Adults with intellectual disabilities in this study preferred IPAQ-s over accelerometer, but IPAQ-s is not validated for use across the intellectual disabilities spectrum. Hence, concurrent validation of IPAQ-s and accelerometer was examined in Chapter 4. The IPAQ-s can also be used to estimate sedentary behaviour. It is free to download, easy and quick to use. For researchers needing to use objective measures of PA such as an accelerometer, this study indicates that further work is needed to explore ways in which accelerometer can be more acceptable to individuals with intellectual disabilities across the spectrum. The participants raised issues relating to accelerometers such as weight (the accelerometer weighed 12-16g), and duration they should be worn – issues that have previously not been reported in the wider population.

2. Recruitment strategy

One way to improve research participation in this population would be to consider recruitment strategies that allow for direct participant/researcher interaction. For example, a researcher could consider recruiting at leisure centres, intellectual disability events, day centres, and other places that individuals with intellectual disabilities visit. Direct access to potential recruit will help to reduce reliance on gatekeepers and hopefully reduce the time spent trying to get past them.

3. Proxy-respondents

Other areas that could benefit from future research is the use of a proxy for consent and response. Even though the reliance on others is well documented in this population, there's a paucity of research (as highlighted in section 3.4.1.1) on how a proxy weighs the information before them as they make choices particularly those decisions that relate to consent. It would be helpful to researchers to know the factors that help a proxy to consent to research.

Clinical message

- PA was measured across the IDS, including in those with severe and profound intellectual disabilities, using an accelerometer and the IPAQ-s.

- IPAQ-s was more acceptable to adults with intellectual disabilities as a PA measure compared to accelerometers.

3.5. Conclusion

It is possible to measure PA using both the accelerometer and the IPAQ-s in adults with intellectual disabilities across the spectrum, but there was a poor response from residential-homes and consequently, a low recruitment rate. Participants were more likely to be living at home, either alone or with their family. Recruitment from residential-homes required more effort compared with those living at home; therefore, greater access is needed to improve research engagement in adults with intellectual disabilities living in residential-homes. With regards to methods of measurement, adults with intellectual disabilities would be happy for the IPAQ-s as a PA measure, but less so for the 7-day accelerometer monitoring. To improve participation in this population, the choice of PA measure is considered important. These are important findings and could inform the design of future PA studies. The author suggests, based on the results of this feasibility study that the accelerometer and IPAQ-s can be used to measure PA in this population regardless of the IDS.

The author recommends that future studies could examine the concurrent validity of both PA measures in adults with intellectual disabilities. Furthermore, they suggest that future studies could examine factors affecting and promoting research participation by residential-homes and other factors such as choice of PA measure, age, and race that may impact on research engagement in this population.

Chapter 4 (Study 3). The concurrent validity of the accelerometer and the short form of the International Physical Activity Questionnaire in measuring physical activity and sedentary behaviour of adults with intellectual disabilities.

4. Summary

The literature review in Chapter 2 demonstrated there is a gap in the literature on the effective measurement of PA and sedentary behaviour of adults with intellectual disabilities, particularly in those with profound disabilities, with most studies excluding them from their research. The result of the review also showed that no subjective PA measure had been validated for use across the intellectual disability spectrum. In Chapter 3, the author discovered that it is possible to measure PA and sedentary behaviour of adults with intellectual disabilities using accelerometers and the IPAQ-s, including in those individuals with profound ID. However, participants complied better with completing the IPAQ-s compared with wearing accelerometers. Consequently, in the current chapter, using the data collected in Chapter 3, the author examined the concurrent validity between the two PA measures, in individuals across the intellectual disability spectrum.

4.1. Introduction

Given the high morbidity and mortality of adults with intellectual disabilities (Krahn, Hammond and Turner, 2006; Emerson and Baines, 2011; Bergström et al., 2013; Heslop et al., 2014), it is important to understand the health-related behaviours in this group, such as PA and sedentary behaviour. For an effective non-communicable disease prevention programmes, policymakers need data for PA levels (Hallal et al., 2012). Accurate assessment of PA and sedentary behaviour is critical to investigating the relationship between PA exposure and health and diseases such as cardiovascular disease, hypertension, obesity, and cancer (Chen and Bassett, 2005; Casperson, 1989). Otherwise, the strength of physical activity/inactivity relationship to a given outcome is likely reduced or eliminated (Casperson, 1989). PA and sedentary behaviour, as discussed in the previous chapter, are assessed either objectively or subjectively. The former is generally accepted to be more accurate, but it has its drawbacks. For example, objective PA measures, such as accelerometers, allow for unbiased measurement and do not have prejudices or problems with the quality of response, issues associated with questionnaires, but accelerometers are expensive, require technical expertise for data download and conversion, and may not be readily available. In addition to these factors,

importantly in Chapter 3, issues of accelerometer adherence and acceptability were observed among adults with intellectual disabilities. On the other hand, subjective methods of measurements such as questionnaires are commonly used (Chapman et al., 2015; Melville et al., 2017; Dairo et al., 2016; Celis-Morales et al., 2012), because they are easy to use and cost-effective, but PA information obtained from self- or proxy-report is potentially subject to recall bias and influence of social desirability (Chapman et al., 2015). In the case of proxy-report, there is the additional source of error as the proxy might not know the individual well or they might not be with them all the time. Hence, it is vital to validate PA questionnaires against an objective measure (Silsbury, Goldsmith and Rushton, 2015; Butte, Ekelund and Westerterp, 2012).

The most commonly used PA questionnaire is the IPAQ (Craig et al., 2003). It is used in PA research and surveillance activities because it has good reliability, acceptable criterion validity, and reasonable classification accuracy compared with accelerometer data (Craig et al., 2003; Lee et al., 2011; Ekelund et al., 2006; Tomioka et al., 2011), and PA related energy-expenditure through the doubly-labelled water method (Maddison et al., 2007). The short-version (IPAQ-s[13]) has been used in the intellectual disabilities population (Matthews et al., 2011; Moss and Czyz, 2016; McKeon, Slevin and Taggart, 2013). Despite globally acceptable measurement properties, the results from some studies indicated limited validity of the IPAQ-s (Craig et al., 2003; Silsbury, Goldsmith and Rushton, 2015). Moreover, its validation studies in intellectual disabilities populations were inconclusive, as well as limited to those with non-profound intellectual disabilities (Matthews et al., 2011; Moss and Czyz, 2016; McKeon, Slevin and Taggart, 2013).

The issue of IPAQ-s validity in people with intellectual disabilities and the potential for recall bias, indicate the need for further research into the validity compared to a gold standard, of its use. Another concern with the use of IPAQ-s that warrants an investigation is the quality of the self- or proxy-response. The IPAQ-s questionnaire is based on recall of PA behaviour over the last seven-day period, but this type of recall could be at the limit of the cognitive abilities of adults with intellectual disabilities (Finlay and Lyons, 2001). In the previous chapter (Chapter 3) it was observed that participants could easily recall PA duration over the last seven days, especially those with mild to moderate intellectual disabilities, but nearly all of them struggled to remember sedentary hours, with only 3 out of 20 able to do so. As a result of the difficulties with recall, the author obtained information from proxy-respondents. Collecting information from proxies in intellectual disabilities research is commonplace. A recent systematic review that examined the measurement

[3] Short version of International Physical Activity Questionnaire (IPAQ-s)

of sedentary behaviour found that most of the studies used proxy-respondent for their data collection (Melville et al., 2017). Despite the reliance on a proxy response for PA and sedentary behaviour data collection within this group, no study has examined the difference between self- and proxy-reported PA and sedentary behaviour.

The purpose of the present study was therefore to assess the concurrent validity of the IPAQ-s and accelerometer for measuring PA and sedentary behaviour in a sample of adults with ID. A secondary aim was to evaluate differences in the self- and proxy-reported PA and sedentary behaviour.

4.1.1. Aims

To explore the concurrent validity of accelerometers and IPAQ-s in measuring PA and sedentary behaviour of adults with intellectual disabilities, including those with profound ID.

4.1.2. Objectives

- Examine the extent of the concurrent validity between the wrist-worn 7-day accelerometer and the IPAQ-s in identifying those that are active or inactive.
- Examine the extent of the concurrent validity between the wrist-worn 7-day accelerometer and the IPAQ-s in determining daily sedentary hours.
- Investigate the extent of the level of agreement between self- and proxy-reported past 7-day PA using the IPAQ-s.
- Investigate the extent of the level of agreement between self- and proxy-completed IPAQ-s in measuring daily sedentary hours.

4.2. Methods

Design: Cross-sectional study of concurrent validity

Participants:

The participants were 20 adults with intellectual disabilities (10 men and 10 women) who participated in the feasibility study in Chapter 3. Participants of the feasibility study all lived in a local authority area in the UK. They were 18 years or older, and had intellectual disabilities diagnosed using recognised diagnostic criteria, or identified as having intellectual disabilities by the social services department or using the specialist intellectual disabilities service or had done so in the past. They lived in the community either at home or in a residential facility. They could communicate in the English language consistently

and effectively with people that they are familiar with and able to tolerate wearing an accelerometer. They did not have a history of acute musculoskeletal injuries, recent history (last one year) of physical violence or self-injurious behaviour, hypersensitivity to a wristwatch or bracelet, or acquired brain (diagnosed in adulthood) / spinal cord injuries. All the participants or their proxy gave a written informed consent and completed the baseline examination, including the LIDT tool which combines seven questions on writing, dressing, speech, preparing food, feeding, empathy, and use of amenities (Tyrer et al., 2008). The tool is used to determine the IDS, and it has a reported diagnostic accuracy of 91% as compared to the Vineland Adaptive Behaviour Scale (de Bildt et al., 2005).

The feasibility study was approved by the by the University Research Ethics Committee (no. 150967) – see Appendix 6.

4.2.1. Data collection

The overview of the procedure for obtaining PA and sedentary data, as well as a detailed description of both the accelerometer and IPAQ-s was provided in Chapter 3 (section 3.2). Briefly, during one home visit, the participants were asked to wear an accelerometer for seven consecutive days during all waking hours. The accelerometer models used were Axivity AX3 (n=8) version V1.2 (Axivity 2013) or GENEActiv (n=9) version 2.9 (ActivInsights Ltd 2013). They were also given a copy of the IPAQ-s for them or their carer/relatives to complete on the eighth day. Additionally, they received a stamped self-addressed envelope for the return of the PA instruments.

Accelerometer-measured PA and sedentary behaviour

Data were obtained from the accelerometer data that were downloaded for the feasibility study. Parameters collected were: 1) how much time (hours/day) a participant spends being sedentary (<217 counts/min) during the day (8am -9pm) for seven consecutive days; 2) daily duration of PA (minutes/day) at light (217-644 counts/min), moderate (645-1810 counts/min), or vigorous (>1810 counts/min) intensities for seven consecutive days. These PA cut-points were based on the study by Esliger et al. (2011) that classified activity into an intensity category of sedentary, light, moderate or vigorous intensities.

To calculate time spent in MVPA/week and for the accelerometer data to be comparable to the IPAQ-s, daily MVPA (the sum of moderate intensity and vigorous intensity minutes multiplied by two) was added up over the seven-day period.

The sedentary hours daytime values for the accelerometer (8 am - 9 pm over the seven days) are summed and divided by the number of days to provide average daily sedentary hours.

Calculation of self- or proxy-reported physical activity and sedentary behaviour

Self- or proxy-reported moderate and vigorous intensity PA levels, and the duration of sedentary hours/day were obtained from the feasibility study data from Chapter 3. In line with the official IPAQ-s guidelines (www.ipaq.ki.se., 2005), data from the IPAQ-s were summed within each item (i.e. vigorous intensity, moderate intensity, and walking minutes) to estimate the total amount of time spent engaged in each category per week. To estimate the MVPA intensity, vigorous intensity minutes/week was multiplied by two and added to the moderate intensity of PA/week. To obtain total PA minutes/week, MVPA was added to the walking minutes/week.

Any reported PA time exceeding three hours/day of activity in any category was treated as an outlier (i.e. they were capped at a maximum of three hours/day) in line with the IPAQ-s scoring protocol (www.ipaq.ki.se., 2005).

4.2.2. Data analysis

There are two parts of the data analysis. Part A details the analysis of the PA data, while part B details that of sedentary hours.

Part A - PA data analysis: Minutes of MVPA intensity from both PA instruments (accelerometers and IPAQ-s) were used to estimate the percentage of participants meeting PAG established by the World Health Organisation (2017b). Briefly, the current minimum weekly aerobic 'global PAG for Health' is that adults should do at least 150 min of moderate-intensity aerobic PA or 75 min of vigorous-intensity aerobic PA throughout the week or an equivalent combination of moderate - and vigorous-intensity activity. These activities should be in bouts of at least 10 min (World Health Organisation, 2011).

PA data from both PA measures were analysed using descriptive statistics with means and standard deviation (SD) calculated. The Cohen's kappa coefficient was used to measure agreement between the two PA measures in identifying those that are active/inactive (Cohen, 1960). Also, a Bland–Altman plot was used to visualise the level of agreement between the two PA measures and analyse heteroscedasticity (Bland and Altman, 2010).

Part B - Sedentary hours data analysis: Means and standard deviation (SD) were calculated for the sedentary hours from the accelerometer and IPAQ-s data. The data were examined for normality in order to use parametric summary. Statistical analysis was performed using a Pearson Correlation coefficient (r) to determine the relationship between the sedentary times from the two measures. The analysis was done for the average daily sedentary hours from the accelerometer and from the IPAQ-s, to determine

the correlation between the two measures. Results were expressed as correlation coefficients (r) representing the relationship between sedentary hours from the accelerometer and that from IPAQ-s. Also, scatter plot, line graphs, and bar charts were used to visualise the relationship between the two PA measures. All analyses were conducted using SPSS for Windows (version 22.0).

4.2.3. Sample size

The author estimated recruiting about 20 participants as described in section 3.2.5 in Chapter 3. The sample size was calculated using G* Power window software version 3.1.9.2. Downloaded from http://www.gpower.hhu.de/en.html. Alpha was set at the traditional significance level of 0.05 (Green, 1991). Power was set at 0.8, a value recommended by Cohen (1988) as appropriate for behavioural research. With a moderate effect size, the study would require 16 participants to test the strength of the correlation between the two PA measures. The same considerations hold for the Kappa's interrater agreement (Cantor, 1996)

4.3. Results

4.3.1. Part A - Physical activity data analysis

Relationship between the accelerometer and the IPAQ-s estimates of PA minutes per week

A scatter plot was used to show the relationship between the accelerometer and the IPAQ-s estimates of PA minutes/week. There was a linear relationship between the PA minutes/week measured by the accelerometer and IPAQ-s, R^2 Linear= 0.34, n=17. When the outlier data were removed as well as an incomplete data, the linear association improved, R^2 Linear = 0.61, n=15 (Figure 4.1).

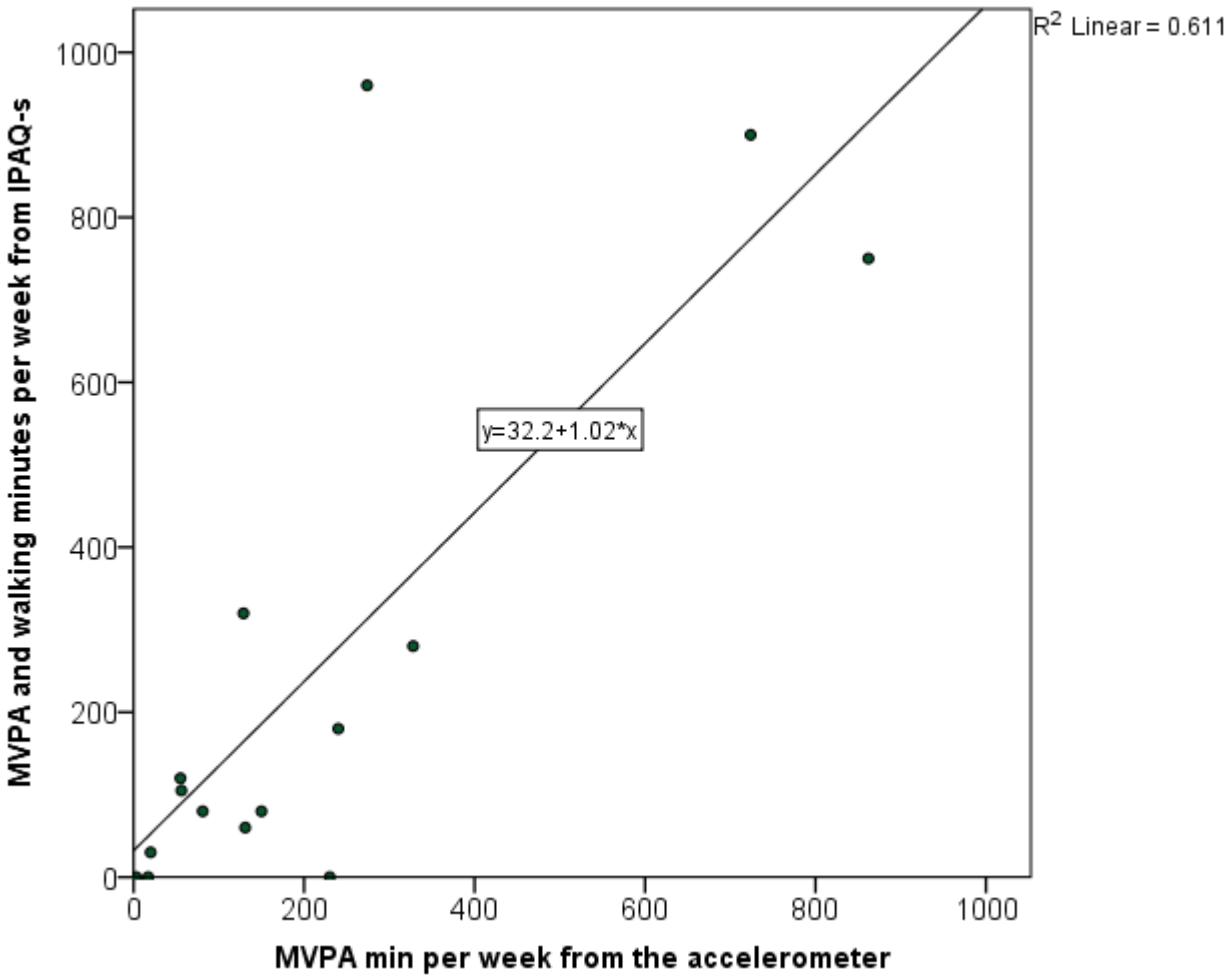


Figure 4.1 PA measured by accelerometer and IPAQ-s (n=15)*

Notes: *one incomplete data and an outlier data were excluded.

Level of agreement between the two physical activity measures

Using Cohen's Kappa, there was a substantial agreement between the accelerometer and the IPAQ-s in identifying participants who met the PAG and those who did not, k= 0.61 $p<0.05$ (Table 4.1). There was a tendency for the IPAQ-s to underestimate minutes of MVPA when compared to the accelerometer values. Twelve out of 16 participants had a higher value of accelerometer MVPA compared with the IPAQ-s. However, this number dropped to seven, when the IPAQ-s walking duration was added to the MVPA time. Two of the participants had almost equivalent data from the accelerometer and the IPAQ-s moderate and vigorous PA minutes (the difference <10 minutes), while one participant's IPAQ-s values overestimated their PA by almost 700 minutes. These results are displayed in the Bland-Altman plots (Figure 4.2). Importantly, the lack of heteroscedasticity demonstrates PA levels do not influence variation between measures. Mean MVPA minutes/week for the accelerometer was 207 (3- 862) and for the IPAQ-s 145 (0-960).

The IPAQ-s mean increased to 269 (0-1200) when the walking minutes were added (Table 4.2). However, removing the outlier and the incomplete data reduced the IPAQ-s mean to approximately 216, while the accelerometer increased to 220.

Table 4.1 Participants who achieved PA guidelines (PAG) with accelerometer compared with the IPAQ-s, n=16*

		Participants who achieved PAG with IPAQ-s (moderate and vigorous PA min/week) and walking min/week		
		Active	Not-active	Total
Participants who achieved PAG with accelerometer (moderate and vigorous PA min/week)	Active	5	1	6
	Not-active	2	8	10
	Total	7	9	16

Notes: IPAQ-s, International PA Questionnaire-short version; PA, physical activity

*one incomplete data was excluded from the analysis

Table 4.2 Descriptive statistics for PA minutes/week measured by accelerometers and the IPAQ-s

	N (%)	Minimum (Minutes)	Maximum (Minutes)	Mean	Std. Deviation
IPAQ-s (MVPA)	20 (100%)	0	960	144.5	257.8
Accelerometer[a] (MVPA)	17 (85%)	3	862	207.1	240.8
IPAQ-s (MVPA and Walking)	20 (100%)	0	1200	269.0	372.3

Notes: IPAQ-s: International PA Questionnaire -short version

MVPA: moderate- or vigorous-intensity physical activity

[a]Two participants had less than seven days data

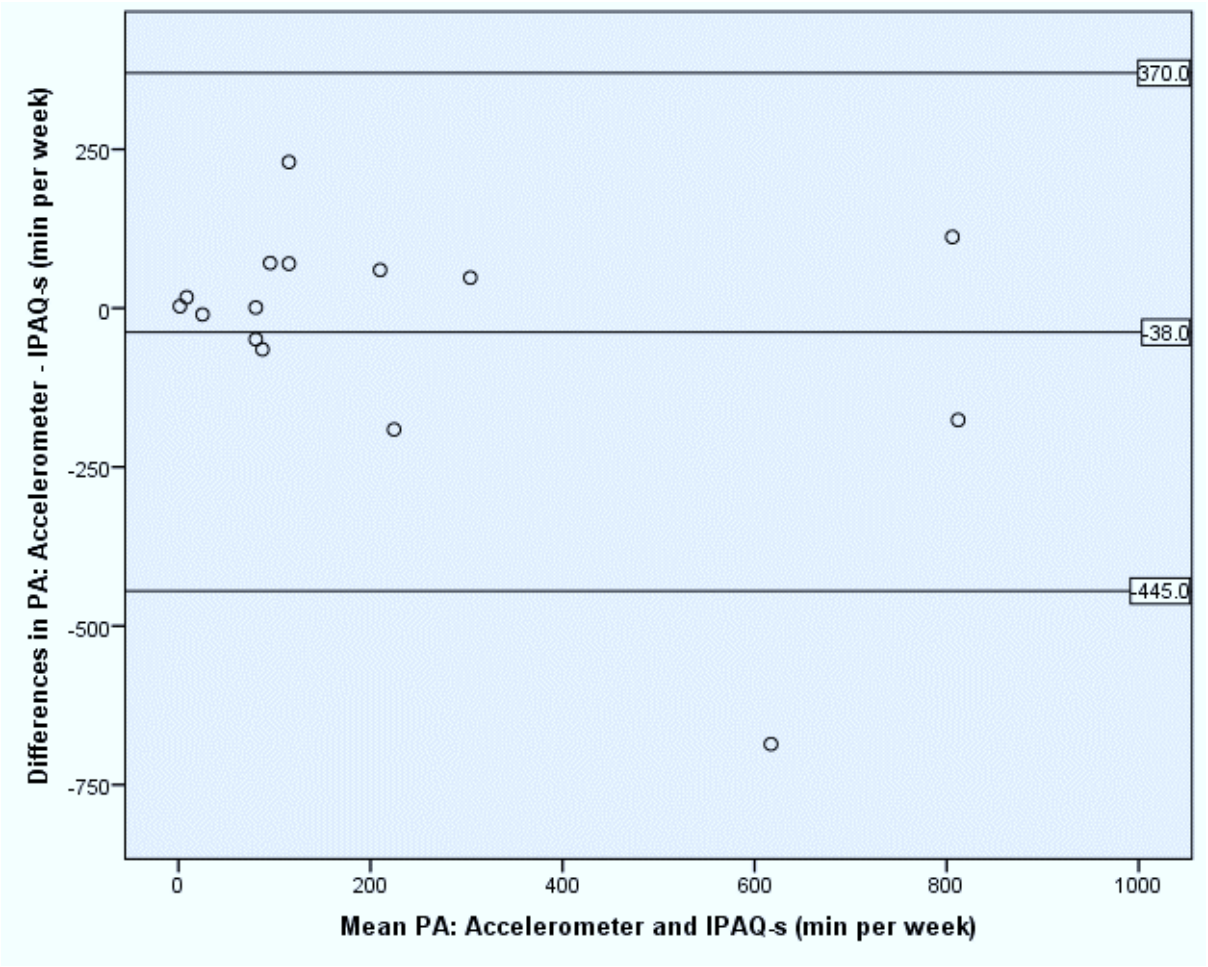


Figure 4.2 PA measured by accelerometer and IPAQ-s (n=15)*

Notes: IPAQ-s: International PA Questionnaire -short version;

*one incomplete data and an outlier data were excluded.

The level of agreement between self/carer completed questionnaire

Seven of the participants could recall PA over the previous seven days using the IPAQ-s. Out of those seven participants who could remember their PA, almost equal number of carers overestimate as underestimate PA minutes/week, but there was a perfect agreement ($k=1$, $p<0.05$) between self/carer recall of PA in identifying participants who were meeting PAG and those who were not.

Participants achieving 150 minutes of moderate intensity physical activity per week

A cross-tabulation of participants that met PAG with Accelerometer and those that achieved it with IPAQ-s (n=16) showed that out of the 16 participants with accelerometer data, only six of them (38%) achieved 150 minutes of moderate intensity PA/week (or its

equivalent). Similarly, the IPAQ-s data indicated that only eight out of the 20 (40%) participants were active (see Table 4.1).

4.3.1. Part B - Sedentary hours data analysis

Results from both PA measures for the 17 participants with sedentary data from both PA measures are presented in Table 4.3 below

Table 4.3 Summary of the descriptive statistics for the accelerometer and IPAQ-s sedentary data, n=17*

	Range	Minimum	Maximum	Mean	Std. Deviation
IPAQ sedentary hours/day	10	4	14	8.12	2.998
Accelerometer sedentary hours/day	6	7	13	10.41	1.583

*Three participants out of 20 were excluded because there were no accelerometer data.

The accelerometer and IPAQ-s estimates of sedentary hours per day

A graph of IPAQ-s values was plotted against accelerometer values (Figure 4.3). There was a tendency for the IPAQ-s to underestimate sedentary hours when compared to the accelerometer values. The IPAQ-s estimates relative to the accelerometer appear consistent for participants that reported being sedentary for part of the day (8 hours or less) and those who are sedentary for most of the day (>8 hours). Eleven out of 17 participants had a higher value of accelerometer sedentary hours/day compared with the IPAQ-s, with the IPAQ-s recording higher values for three participants. Three of the participants had equivalent data from the accelerometer and the IPAQ-s sedentary hours/day (10,11, and 12 hours). Similarly, a scatter plot confirmed the linear relationship between the two measures (Figure 4.4).

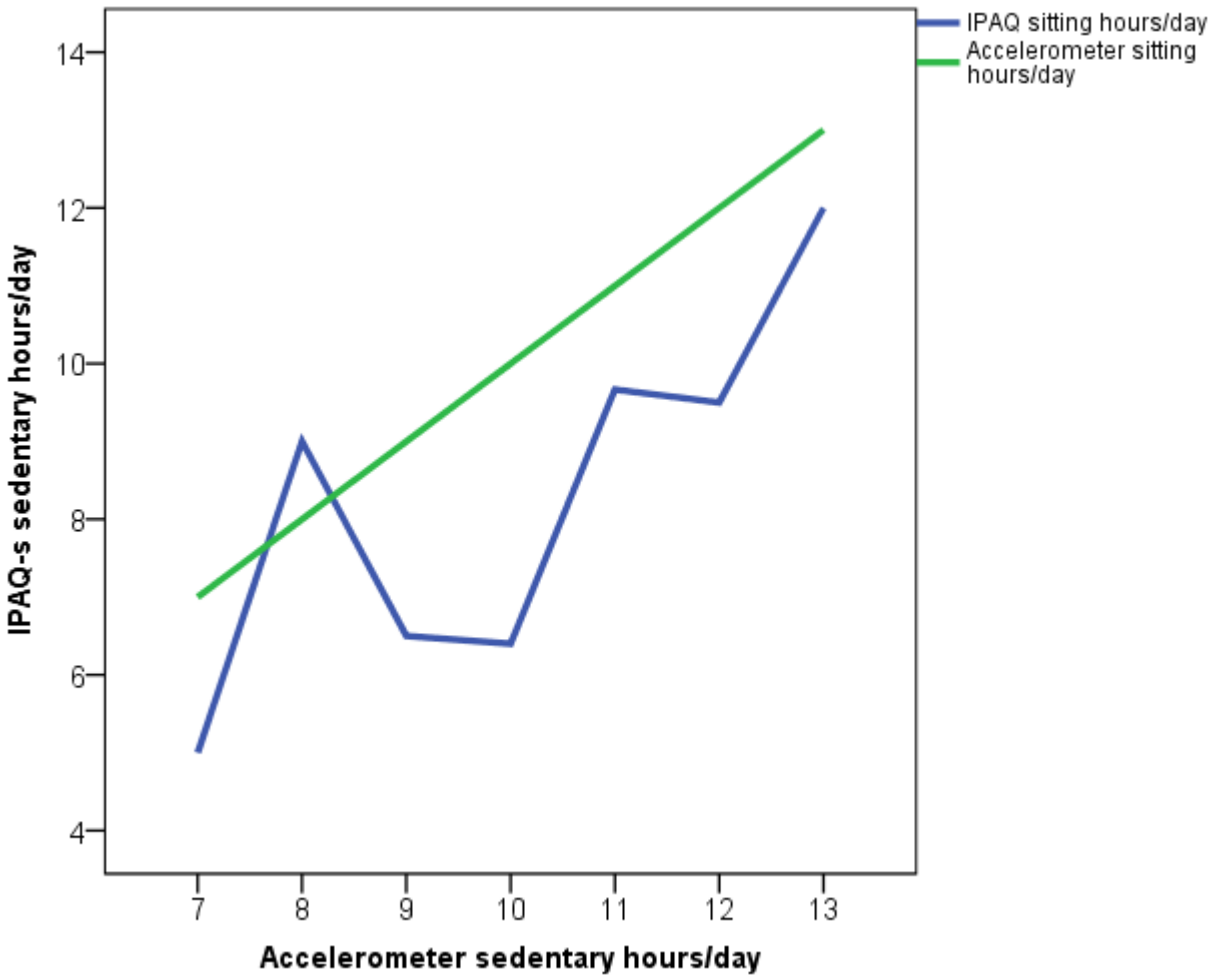


Figure 4.3 Individual estimates of the IPAQ-s compared against accelerometer sedentary hours/day

A Pearson correlation coefficient was computed to assess the relationship between the accelerometer and IPAQ-s estimates of sedentary hours/day. There was a positive correlation between the two variables, r = 0.50, n = 17, p = 0.04. A scatter plot summarises the results (Figure 4.4). Overall, there was a moderate, positive correlation between the accelerometer measured sedentary hours/day and the IPAQ-s self- or proxy-reported hours/day. Increase in the accelerometer values of sedentary hours was correlated significantly to increase in IPAQ-s sedentary hours.

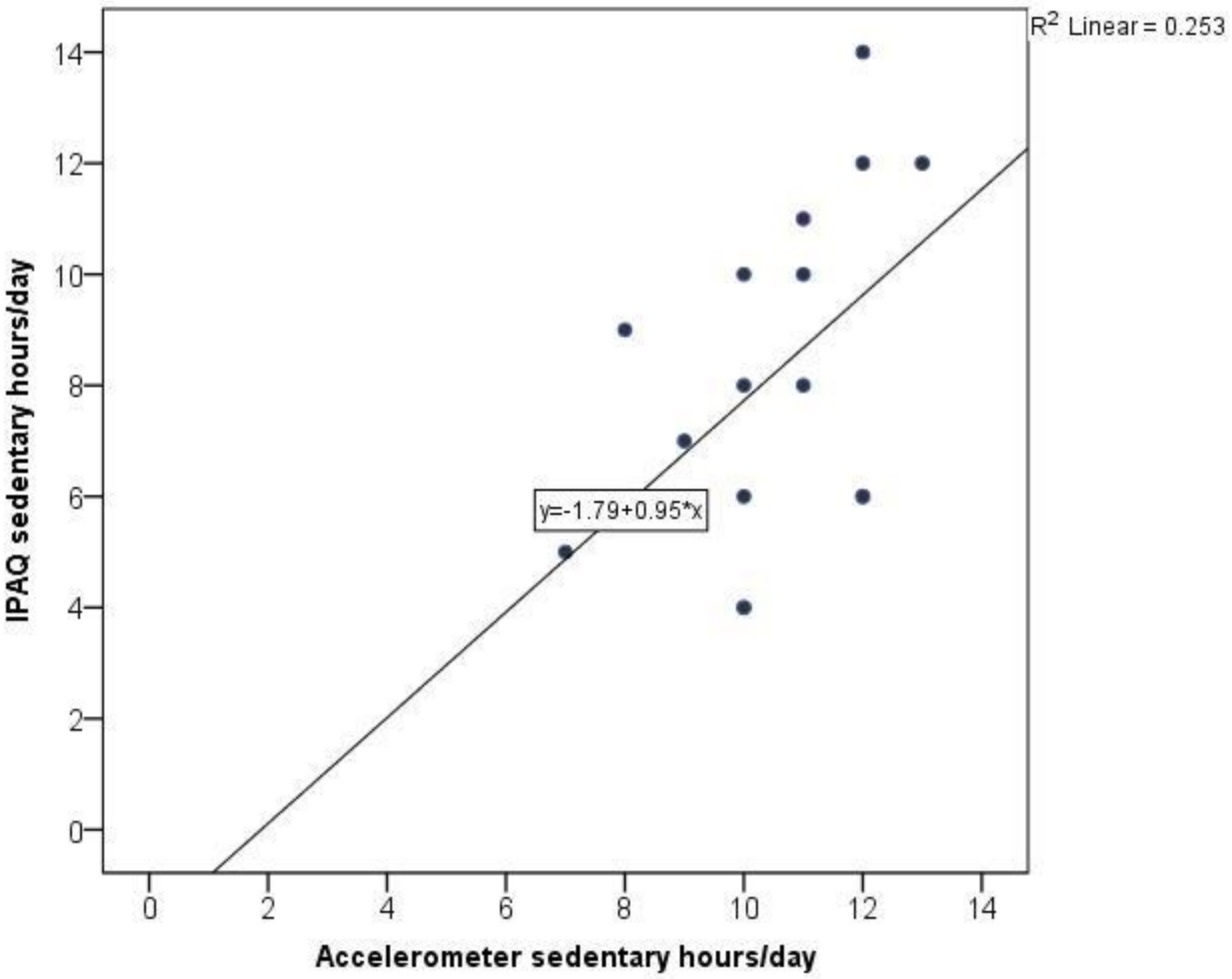


Figure 4.4 Relationship between the accelerometer-derived sedentary hours/day and IPAQ-s sedentary hours/day

Comparison between self- and proxy-reported questionnaire

The sedentary hours measured by the accelerometer and IPAQ-s is shown in Figure 4.5. Only 3 out of 17 participants (numbered 5, 11, and 14) could self-report their daily sedentary hours while all others were proxy-report. All three participants that recalled their sedentary time had mild IDS, although one of those that had proxy-report also had mild IDS (see Table 3.2 in Chapter 3 for their demographic data). Participants represented by number 3, 5, 7, and 14 had the greatest disparities between the reported and measured sedentary hours, two of whom were self-report (2 out of 3 self-reports). Three of the proxy-reports (6, 16, and 17) had a perfect agreement with the accelerometer data.

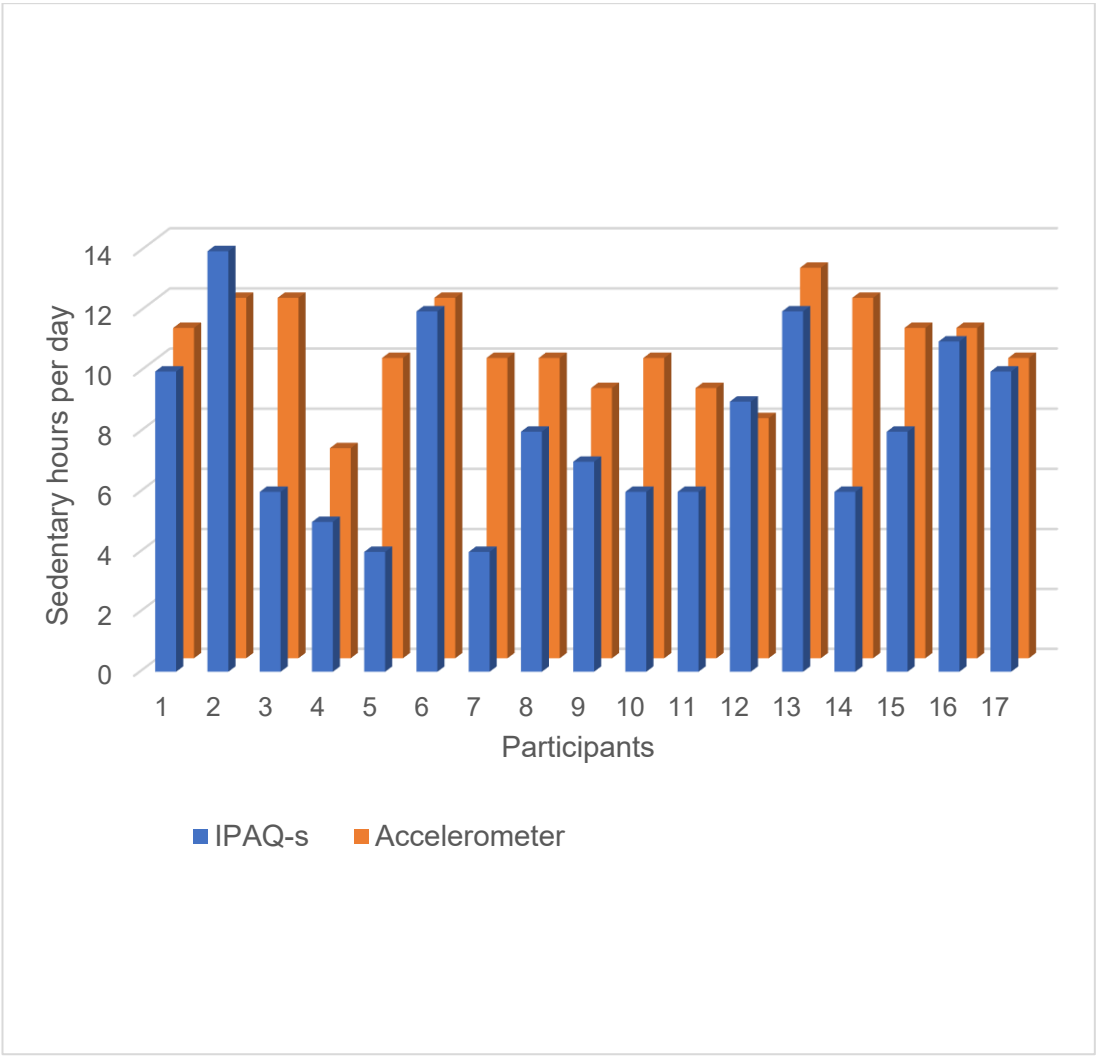


Figure 4.5 Comparison between sedentary hours measured by the accelerometer and IPAQ-s (n=17)

Notes: IPAQ-s, International PA Questionnaire-short version

4.4. Discussion and Conclusions

4.4.1. Discussion

Substantial agreement was found between the accelerometer and the IPAQ-s as a measure of PA in this population when the outcome is a judgement about the PA level

that achieves health benefit (i.e. whether an individual is active or not as determined by the PAG). However, the minute by minute measurement of PA by IPAQ-s tended to underestimate moderate-vigorous PA in comparison to the accelerometer. In addition, the significant correlation between the accelerometer and the IPAQ-s in measuring sedentary hours/day indicates that the IPAQ-s could be used in estimating sedentary behaviour, which is essential for identifying those most at risk of inactivity and prolong sitting hours, a risk factor for all-cause mortality (Chau et al., 2013).

With regards to the recall of PA and sedentary behaviour, participants with milder severity could recall PA over the previous seven days, and their recall was as good as that of their carer in determining whether they were active or not. However, the author found that the participants had greater difficulty in recalling sedentary hours compared to their recall of PA. Only the participants with mild severity could recall sedentary hours over the previous seven days, but their recall of sedentary hours was different to the objectively measured hours. None of the participants with moderate, severe and profound intellectual disabilities could remember or estimate their sedentary hours despite the use of prompts (as recommended in the IPAQ-s scoring guide). The challenge with the recall, probably explains why previous studies that measured sedentary behaviour in this population used proxy- respondents (Matthews et al., 2011; Moss and Czyz, 2016). It is also consistent with the finding that the recall of 7-day PA is at the limit of the cognitive ability within this group (Finlay, W., Lyons, E., 2001). Nevertheless, it is interesting that the participants could remember the actual PA (type and duration) over the previous seven days (see Chapter 3), but not sedentary hours despite both relying on recall. It is likely that quantifying time may have contributed to the difficulty in their recall of sedentary behaviour.

Concurrent validity

The results from the concurrent validation of the IPAQ-s against accelerometers suggest that the IPAQ-s was more acceptable than the accelerometer. It also shows that the IPAQ-s underestimates the absolute moderate-vigorous PA levels. While this contrasts with previous studies of the wider population (Lee et al., 2011), it is consistent with a previous study of people with intellectual disabilities (Matthews et al., 2011). Despite the difference in the estimate of the PA levels between the IPAQ-s and accelerometer, the substantial agreement between the two in identifying those who were active against those that were not, is good enough to indicate that the IPAQ-s could be used both clinically and for research in this population to determine those who are active or not active. However, the author would recommend a bigger study to investigate the reliability of the difference in PA minutes/week between the two instruments.

Similarly, the IPAQ-s underestimates sedentary hours/day compared with the accelerometer. This is consistent with previous studies within an intellectual disabilities population (Matthews et al., 2011; Moss and Czyz, 2016) and studies in the wider population (Celis-Morales et al., 2012). Despite the difference in the accelerometer's sedentary behaviour and IPAQ-s' estimates, there was a significant positive correlation between the two measures, suggesting that the IPAQ-s could be used both clinically and for research in this population to measure sedentary behaviour. The correlation result is consistent with previous studies of the wider population, which reported a significant correlation between accelerometer's sedentary behaviour and IPAQ-s' estimates (Celis-Morales et al., 2012). It is also comparable to findings from a recent study in intellectual disabilities population where a significant correlation was observed between the accelerometer (ActiHeartVR) and IPAQ-s as measures for sedentary behaviour ($r = 0.31$; $p = 0.04$) (Moss and Czyz, 2016). However, Matthews et al. (2011) in their study of PA and sedentary behaviour of adults with intellectual disabilities, reported that there is a limited agreement between the accelerometer and proxy-respondent IPAQ-s. Matthews study did not give information about their proxies, precisely how well they know the participant – an important factor in proxy's response accuracy (Magaziner et al., 1996), hence, it is difficult to determine whether the quality of proxy's response influenced their results.

Inter-rater agreement - Physical activity measures

The Cohen's Kappa shows a perfect agreement between the carer- and self-completed IPAQ-s, in identifying participants who are meeting the PAG and those who are not. The strength of inter-rater reliability coefficients like Cohen's Kappa is that it is a gauge of the quality and the clinical value of observations characterising an individual (Kraemer and Jacklin, 1979; Shrout, 1998). Kottner (2008) argued that although high proportions of inter-rater agreement are important, statistics such as the Cohen's Kappa provide information about the clinical value of the ratings (Kottner, 2009). In this study, the significant kappa statistics show that both self and carer recall of PA can reliably identify those who are active/inactive. This suggests that carers' recall of PA is accurate. There is no other study in this population to compare the current findings with as there is no comparable data on the agreement between raters from published studies, but factors influencing concurrence can be gleaned from proxy response studies. Those studies have found that concurrence between participants and their proxy is enhanced when the proxy knows the person well and has regular contact (Magaziner et al., 1996); when the proxy respondent is asked to recall actual behaviour, and when the variables of interest are observable (Magaziner et

al., 1997). In the current study, the proxy was either family or carers who were asked to recall PA behaviour and had known participants for at least six months. They could recall PA behaviour both within and outside of the participant's home. These may explain the perfect agreement on PA between raters observed in this sample.

Inter-rater agreement - Sedentary behaviour measure

In this study, data were obtained for sedentary behaviour, either from the participants or their proxy. To that end, it is not possible to compare inter-rater responses. However, the agreements between the accelerometer and IPAQ-s varied depending on if the IPAQ-s was a proxy- or self-respondent. Some proxy-responses had a perfect agreement with accelerometer data while self-report tended to underestimate sedentary hours. In the literature, there is conflicting evidence of the agreement between the sedentary time measured with a proxy-report questionnaire and that of accelerometer data. For instance, Matthews et al. (2011) found that sedentary time measured with a proxy-report questionnaire often did not agree with accelerometer data. They observed a substantial variation in the level of agreement between the accelerometer and the proxy-response IPAQ-s. They suggested that it may be due to the heterogeneity of carers completing the IPAQ-s. In this study, although the proxy respondents were heterogeneous, it was stipulated that a proxy should have known the participants for at least six months. In contrast to the study by Matthews et al., a recent study (Moss and Czyz, 2016) on the level of agreement between objective PA and subjective proxy-respondent found a weak but significant correlation between accelerometer data and IPAQ-s instruments for sedentary behaviour, $r = 0.31$; $p = 0.04$(Moss and Czyz, 2016). Although both studies used the 7-day accelerometer and proxy-response IPAQ-s to measure sedentary hours, neither gave information about the proxies, on how long they knew the participants, an important factor in determining the quality of proxy's response.

4.4.2. Strengths and Limitations

This study showed for the first time that PA and sedentary behaviour in this group could be measured effectively using a subjective method (the IPAQ-s) as evidenced by its concurrent validity with the accelerometer. However, the accelerometer cut-points used in this study were based on the validation study in a healthy population (Esliger et al., 2011). To the author's knowledge, only one study has investigated activity cut-points in individuals with ID, but it was a small study consisting only of individuals with Down syndrome (Agiovlasitis et al., 2011). Although they found that the vigorous intensity cut-

off for adults with intellectual disabilities was lower than for non-disabled adults, in contrast, the moderate activity cut-point was within the range of the wider population. Furthermore, the study did not report cut-points for sedentary behaviour or light PA, reporting only cut-points for moderate and vigorous PA. Importantly, previous intellectual disabilities studies that reported accelerometer analysis parameters (Dixon-Ibarra, Lee and Dugala, 2013; Phillips and Holland, 2011), used cut-points for the wider adult population similar to the ones employed in this study. To date, no published studies have examined the validity of the sedentary behaviour cut-points for adults with intellectual disabilities. Although results from observational studies suggest that adults with intellectual disabilities expend significantly more energy during sedentary behaviours than adults without intellectual disabilities (Lante, Reece and Walkley, 2010; Ohwada et al., 2005), it is unlikely that the difference in energy expenditure in people with intellectual disabilities would lead to an underestimation of sedentary behaviour by accelerometers when using Esliger's cut point for sedentary behaviour (<217 counts/min). This is because this cut -point for sedentary behaviour is higher than the <100 counts/min, the most commonly used cut point for sedentary behaviour (Gorman et al., 2014). Additionally, existing data in the intellectual disabilities population consistently report higher accelerometers sedentary hours compared to the IPAQ-s reported values (Matthews et al., 2011; Moss and Czyz, 2016).

Another strength of this study is that the proxies knew the participants well, increasing the likelihood of an accurate response to the proxy-reported measures. Although the relatively small number of proxies and indeed the whole sample limits the generalisability of the findings, it is anticipated that it will contribute to the evidence for the use of proxies for questionnaires and surveys in this population. Finally, the participants were more active (accelerometer and IPAQ-s data indicated that 6/16 (38%) and 8/20 (40%) were active respectively) compared to the 9% that was observed in the intellectual disabilities population in study 1 (Chapter 2). This indicates that the sample is skewed towards more active individuals. Nevertheless, this is the first time that the concurrent validity of the accelerometer and IPAQ-s data in identifying those who are active/inactive has been established in this population across the range of ID.

4.4.3. Clinical message

- IPAQ-s was as good as accelerometers in identifying those who were active/inactive with reference to the PAG. This suggests that if the outcome of PA measurement is a

binary outcome such as identifying those that are active and those that are not, then the IPAQ-s can be used.

- Adults with intellectual disabilities' recall of PA using the IPAQ-s was accurate; however, recall of sedentary behaviour was less so.
- Although adults with intellectual disabilities have difficulty in estimating how much time they spend sitting or reclining, their carer's estimate was mostly accurate.

4.5. Conclusion

There was a substantial agreement between accelerometers and the IPAQ-s in identifying adults with intellectual disabilities who were active and those that were inactive. Also, the IPAQ-s was more feasible compared to the accelerometer as a PA measure in this population, but it slightly underestimated PA levels. However, it did so consistently at low, as well as high PA levels. Additionally, there was a perfect agreement between the carer- and self-report of PA in identifying those who are active and those that are inactive, signifying that carers can accurately report PA. These are important findings and could inform the design and intervention of future PA studies.

For the assessment of sedentary behaviour, it was observed that adults with intellectual disabilities struggled to recall or estimate the amount of time they spend being sedentary in a day; however, the proxy-report of sedentary time closely matched accelerometer measurements, indicating that the proxy-report of sedentary behaviour is accurate. Both self- and proxy-report of sedentary behaviour has a moderate positive correlation with the accelerometer estimates. These findings demonstrate that the IPAQ-s can be used to measure PA and sedentary behaviour of adults with intellectual disabilities, important if we are to identify those who are inactive in this population. As this is a small study, the author recommends the measurement of PA using IPAQ-s in a bigger sample of adults with intellectual disabilities to further the evidence of its use in this population.

Chapter 5 (Study 4). Physical activity levels of adults with intellectual disabilities, and the development, construct validity, and test-retest reliability of a single-item physical activity intention measure for adults with intellectual disabilities.

5. Summary

The results from Chapter 4 show that there is a substantial agreement between the accelerometer and the IPAQ-s in identifying participants who were active and those who were not, but there is a tendency for the IPAQ-s to underestimate minutes of MVPA when compared to the accelerometer values. Similarly, the IPAQ-s underestimated sedentary hours compared to the accelerometer data. However, there was a significant positive correlation between sedentary hours measured by the IPAQ-s, and sedentary data from the accelerometer. In addition to the concurrent validity, the author discovered that adults with intellectual disabilities could tell you whether they are active or not and so can their relatives/carers without the need for expensive equipment. Consequently, in the first part of the fourth study, PA levels were measured across the intellectual disability spectrum using the IPAQ-s. In the second part, in order to investigate readiness to change PA behaviour in this group, a single-item PA intention measure (SPAIM) was developed, and it was incorporated into the IPAQ-s measurement. The construct validity and reliability of the SPAIM was also examined, as well as the relationship between PA intention and PA levels.

5.1. Introduction

Having found in the previous chapters that the IPAQ-s was a valid measure of PA levels of adults with intellectual disabilities, this chapter sets out to measure PA levels in a representative sample, across the full spectrum of the IDS. As discussed in Chapters 1 and 2, only few studies have collected PA data in large samples of adults with intellectual disabilities, and none had used validated measures across the spectrum. Consequently, there is a lack of population-based data describing levels of physical activities in this group (Moss and Czyz, 2016). In those studies that have collected PA data, they tend to report moderate to vigorous PA, with only a few exceptions reporting sedentary behaviour (Phillips and Holland, 2011; Melville et al., 2017). In order to implement effective non-communicable disease prevention programmes, policymakers need data for PA levels

and trends (Hallal et al., 2012). Thus, this study measured PA and sedentary behaviour using the IPAQ-s, in a representative sample of adults with intellectual disabilities.

The second part of this study is about the PA behaviour of adults with intellectual disabilities. The previous chapters of this thesis demonstrate low levels of PA and high sedentary behaviour among adults with intellectual disabilities. To increase PA and reduce time spent in sedentary behaviour, we need to understand better the complex influences that underpin low activity behaviour. Behavioural theorists identified three factors necessary for volitional or intentional behaviour (Fishbein et al., 2001). They are the skills to perform the behaviour, the intention to do the behaviour, and the absence of environmental constraints that make it impossible to perform the behaviour. Besides these factors, individuals with an intellectual disability could have additional factors linked to their disabilities which may affect their behaviour. Among these are: differences in health status (Krahn, Hammond and Turner, 2006; Emerson and Baines, 2011; Haveman et al., 2011; Heslop et al., 2014); the reliance on others for tangible support (Bodde & Seo, 2009; Temple & Walkley, 2007); paid carers' preferences (Cartwright et al., 2017); the severity of intellectual disabilities (Dairo et al., 2016); and financial vulnerability (Hawkins and Look, 2006; Temple and Walkley, 2007; Emerson and Parish, 2010).

Those three components of behaviour identified by Fishbein et al. (2001), are well documented in research involving the wider population, and to some extent those in people with intellectual disabilities. For example, there are measures available to assess individuals' skills to perform PA, and there are studies of PA barriers. However, there is no accepted measure of PA intention in intellectual disabilities populations. Intention can be used as a proximal measure of behaviour, can predict behaviour (Ajzen, 1991; Ajzen and Fishbein, 2001; Francis et al., 2004; Schifter and Ajzen, 1985), and it is an important factor in behavioural change theoretical framework such as the theory of planned behaviour (TPB) (McEachan et al., 2011; Francis et al., 2004; Ajzen, 1991). In addition to not having a measure of PA intention in intellectual disabilities populations, theoretical behavioural frameworks are rarely applied to intellectual disabilities population in assessing barriers to PA, whereas they are often used in relation to the wider population (Bodde and Seo, 2009). This difference is not surprising. Existing behavioural theories used within non-ID populations for instance, the TPB (McEachan et al., 2011; Francis et al., 2004; Ajzen, 1991), self-efficacy (Bandura, 1994), self-determination (Deci and Ryan, 2008), goal-setting (Hall, K and Kerr, 2001), and the capability, opportunity, and motivation, behaviour system (COM-B) (Van Aerde, 2015; Michie, van Stralen and West, 2011), require cognitive competencies that might make them unsuitable for use in their

entirety in people with intellectual disabilities. However, modifications to the theories to accommodate reduced ability to understand new and complex information could impact on their concept validity.

5.1.1. A brief literature review of behavioural assessment and theories in intellectual disabilities

To the author's knowledge, the only studies to use intention in relation to the health behaviours of people with intellectual disabilities were aimed at their carers (Jenkins and McKenzie, 2011; Martin et al., 2011). Although some studies of this population have used psychological theories such as the Social Cognitive Learning Theory (SCLT) (Bandura 1997) and the Transtheoretical Model of Change (TTM) (Prochaska & DiClemente 1983), the majority focused on the assessment or predictors of motivation for sport participation (Hutzler and Korsensky, 2010), Travis and Sachs (1991) , Heller, Hsieh and Rimmer (2004) Stanish and Frey (2008), and Frey (2007). Considering the intricacies of these theories and the level of abstraction involved in using them, it remains unclear how effective they would be at informing the construct of a measure that can provide formative principle to behavioural change frameworks for adults with intellectual disabilities, especially those with severe and profound ID. For instance, the SCLT (Bandura 1997), one of the most recognised theories that deal with cognitive and emotional aspects contributing to behavioural change, is commonly used in the wider population to explain motivational factors for PA (Roberts et al. 2007). One of the concepts underpinning the SCLT theory is perceived self-efficacy, which is defined as people's beliefs in their capacity to produce designated levels of performance that exercise influence over events affecting their lives (Bandura, 1994). Crucial to this is a high level of cognitive ability and the skill to assess social expectations and evaluate challenges. When it comes to applying the concept of self-efficacy to PA behaviours in persons with ID, it may be asked whether these cognitive aspects are meaningful (Hutzler and Korsensky, 2010).

In a systematic review of motivational correlates of PA in individuals with an intellectual disability, Hutzler & Korsensky (2010) showed that there are frameworks for behavioural change interventions for PA and sports motivation in people with ID, equally, they raised questions about whether those frameworks achieved what they set out to do. The review consisted of 23 articles focusing on motivational correlates that either contributes to or are the outcomes of, participation in sport and recreation or health-related physical activities. For the most part, it was difficult to make sense of their findings due to methodological issues with their review. They did not explain why they included studies on behavioural change with different designs (cross-sectional, qualitative, experimental, and longitudinal

intervention designs) or state the criteria that they used for their evaluation of those studies (except for the intervention studies). What is more, there was no distinction made between studies that used behaviour change frameworks as a predictor of PA behaviour and those that used them as an intervention. Additionally, it would be difficult to generalise their findings as their review data was informed by highly selective studies consisting mostly of adolescents and young adults, and limited to individuals with mild to moderate intellectual disabilities with the exception of one small experimental study consisting of 5 adolescents with profound intellectual disabilities (Owlia et al., 1995). Notwithstanding these limitations with the systematic review, it is possible to conclude from the review that the use of behavioural change frameworks within intellectual disability populations is challenging.

5.1.2. Physical activity levels and intention

Although studies of motivation in intellectual disabilities populations suggest reasons why individuals may wish to be physically active, we have no understanding of the intention to be active within an adult intellectual disabilities population. An act of intending is 'a volition that you intend to carry out' (Vocabulary.com, 2017). In a study analysing volitional behaviour, Kantor (1923) suggested that the most typical feature of an intention, is to be informed that something must be done and knowing the expected result, but just how the activities will be performed is subject to the particular behaviour's situation. As identified by behavioural theorists, intention is a key factor in volitional behaviour (Fishbein et al., 2001; Fisher, 2014). Additionally, studies in the wider population have shown links between intention and behaviour (Schifter and Ajzen, 1985; Ajzen, 1991; Ajzen and Fishbein, 2001).

Physical inactivity behaviour is a modifiable health risk for most people (Warburton, Nicol and Bredin, 2006). Ajzen and Fishbein (1980) and Ajzen (1991) suggest that the main determinant of behaviour is the person's intention to perform a specific behaviour (e.g. 'I intend to walk for 30 minutes every day over the next one week'). Therefore, it is likely that people who have positive intentions will be more likely to exert the effort required to achieve their goals. Measuring PA intention would be useful for changing PA behaviour in adults with intellectual disabilities as understanding the antecedents to their behaviour could have a transformative effect on identifying those who need PA intervention and health promotion. Measurement tools used within intellectual disabilities populations should reflect the difficulties associated with this group such as problems with learning and applying new skills, following through with unfamiliar tasks, and dependence on others. It should, therefore, be simple, easy to use and understand without placing too

much burden on the individuals, their carers or families, and health professionals. Besides, there is a demand to establish standardised brief measures, that can be completed when time and resources are limited (Milton, Bull and Bauman, 2011). Consequently, a simple single-item measure of PA intention that is unique to this population was developed. It was designed to supplement the IPAQ-s measurements. The construct validity and test-retest reliability of the measure was also examined, as well as the correlation between PA intention and reported PA and sedentary levels. Admittedly, single-item and self-report measures or questionnaires have weaknesses that are well documented (Shephard and Vuillemin, 2003; Prince et al., 2008; Milton, Clemes and Bull, 2013; Reissmann et al., 2013). However, they are cheaper, capture a wider audience, and are easier to administer than other research methods such as interviews and longitudinal studies (Litwin, 1995; Sallis, Bauman and Pratt, 1998; Nardi, 2006).

The choice of a measuring tool depends on the research objectives as well as on the available resources and expertise (Shephard and Vuillemin, 2003). As a result of low levels of PA in adults with intellectual disabilities, there is a need to describe their PA and sedentary behaviour, as well as predicting their PA levels. So as to address this need, the PA levels of adults with intellectual disabilities were measured, and an intention measure that could be incorporated into the PA measurement was developed.

5.1.3. Study Aims:

There are two aims of this study:

1. To measure PA levels of adults with intellectual disabilities
2. To develop a simple single-item measure of PA intention, and examine the relationship between PA intention and the PA and sedentary behaviour of adults with intellectual disabilities.

5.1.4. Study objectives

1) To measure PA minutes/week and sedentary hours/day of adults with intellectual disabilities in a community setting (i.e. not in residential care), using the IPAQ-s to establish their PA levels.
2) To examine the extent of the relationship between PA and sedentary behaviour of adults with intellectual disabilities and their age, sex, type of residence, and the severity of their intellectual disability.
3) To work with experts and adults with intellectual disabilities to develop a simple single-item measure of their intention towards being physically active.
4) To assess the construct validity of the single-item measure by examining the ability of adults with intellectual disabilities to demonstrate that they understand the

meaningfulness of a) the time duration used in the measure and b) PA by citing an appropriate example(s).

5) To assess the test-retest reliability of the single-item measure in the community settings.
6) To compare the reliability of the results of a 5-point rating scale of the measure, to that of a 3-point one.
7) To examine the PA intention and its relationship with PA and sedentary behaviour of adults with intellectual disabilities across the disability spectrum.

5.2. Methods

5.2.1. Study design and setting

Study 4 was carried out in three phases as described below. PA was measured throughout the phases using the IPAQ-s.

1. Phase one consisted of the intention measure development;
2. Phase two had two sub-studies, the construct validity and test-retest reliability of the measure; and
3. Phase three, a cross-sectional study to examine PA levels in a representative sample of adults with intellectual disabilities, and the correlation between reported PA levels and PA intention.

Setting: All three phases of this study were carried out in the community between June and December 2016 in Oxford, UK.

Sampling: A convenience sampling method was used (Owen et al., 2014) rather than a random sampling because of time and resource implications.

Recruitment: Participants were recruited by the author approaching an unselected sample of consecutive adults with intellectual disabilities attending day centres, intellectual disability events, and sports centres in Oxfordshire.

In addition to the participants, clinicians with expertise in intellectual disabilities and experts in research methodologies and PA were recruited.

Inclusion: All adults with intellectual disabilities living in Oxfordshire.

Exclusion: Initially, there were no exclusions. Subsequent exclusions were applied to determine eligibility into the two sub-studies in phase two.

The study was prepared and reported with reference to the 'STROBE -A checklist to Strengthen the Reporting of Observational studies in Epidemiology' (Knottnerus and Tugwell, 2008; Langan et al., 2011).

5.2.2. Ethical considerations and consent procedures

Ethical approval was granted by the University Research Ethics Committee (UREC) no: 150967. Approval is described in chapter 2 section 2.2 with the amendment request attached as Appendix 7 (Amendment version 1). Participation in the survey by the participant was taken as implied consent. Where the individual could not consent, in line with the MCA (UK government Department of Health, 2005), a proxy decision-maker (family /carer) was identified, with the carer required to have known the participant for at least six months.

5.2.3. Phase one

Design: The development of the measure

A single-item PA intention measure (SPAIM) was developed for use in adults with intellectual disabilities as a suitable measure to understand their intention towards being physically active. The use of a single-item measure of PA is not new with a published review and other observational studies highlighting their measurement properties (Milton, Bull and Bauman, 2011; Gill et al., 2012; Silsbury, Goldsmith and Rushton, 2015). One of the studies (Milton, Clemes and Bull, 2013) included in the Silsbury, Goldsmith and Rushton's (2015) review and rated as good based on the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) (Mokkink et al., 2010), examined the criterion validity of a single-item PA measure against accelerometry in healthy adult populations. It showed a significant criterion validity against an accelerometer for moderate to vigorous PA, k=0.23, 95% CI 0.05 to 0.41; and PA ≥10 min bouts 0.39 (95% CI 0.14 to 0.64) (Milton, Clemes and Bull, 2013). Although the study was on the criterion validity of an observable aspect of PA, it served as a useful guide for establishing a single-item measure of PA. The SPAIM was designed to obtain information about the attitude towards future PA behaviour and to understand the variance of intention (within the population) towards being active. It was constructed to reflect the desired PA behaviour based on the current UK PA guidelines (Chief Medical Officer, 2011) of 'a minimum of 30 minutes' moderate PA or its equivalent, for at least five days in a typical week'. It was limited to choosing pre-selected options to show whether an individual has

a positive or negative PA intention. The SPAIM is a researcher-administered single-item question about an individual's intention to be active. Its rating scale offered three directions of positive, negative and neutral of -2 to 2, where: -2= Very unlikely; -1= Unlikely; 0=Neutral; 1= likely; 2= Very likely. The process of developing the questionnaire is detailed below.

Item refinement and pilot

The SPAIM was primarily designed to provide an insight into the PA intention; therefore, a pragmatic approach to its development was adopted, using a single-item measure. The tool was refined in collaboration with adults with intellectual disabilities, clinical and research specialists in the field of intellectual disabilities. Initially, the one-item questionnaire was developed by the author as shown below:

I would like to (insert physical activity of choice) _____ for a minimum of 30 minutes, at least five days in a week.

Very unlikely *Unlikely* *Neutral* *Likely* *Very likely*

The single-item questionnaire was then shown to a group of people with intellectual disabilities (n=11) to assess whether the question was clearly worded and understood easily. Ten out of the 11 participants answered the questions independently and without prompting. However, one participant struggled with 'inserting PA of choice'. Consequently, the measure was reviewed in detail with two experienced researchers and five clinicians (three physiotherapists, a nurse, and an occupational therapist) working in the clinical area of intellectual disabilities. Based on the feedback from the researchers, the measure was refined to improve the clarity of wording by specifying the meaning of PA, i.e., doing something that involves standing or moving around. This was to increase consistency of the measure. The procedure for delivering the measure was refined following feedback from clinicians to standardise its delivery for optimising fidelity of its implementation. The expert consensus was that:

a) In the first instance, the SPAIM should be administered to the individual
b) If they were unable to answer the SPAIM question, consider using prompts as advised by carers/relatives
c) If they were unable to answer it with prompts, then consider the use of a proxy. The proxy must have known the individual for at least six months.

Consequently, the measure and delivery procedure was refined and the resultant item was pilot tested on five participants, all of whom responded to the question without prompt

or assistance from their proxy. There were no changes made to the question following the pilot.

Final questionnaire

The final questionnaire consisted of a researcher-administered single-item question about the individual's future intention towards being active. It was a closed-ended questionnaire with responses about PA intention coded on a 5-point intensity scale of -2 to 2, where: -2= Very unlikely; -1= Unlikely; 0=Neutral; 1= likely; 2= Very likely, as shown below:

I would like to get up from my seat and do something that involves either standing or moving around, for a minimum of 30 minutes, at least five days in a typical week.

Very unlikely *Unlikely* *Neutral* *Likely* *Very likely*

Scoring

The author asked the participants which of the five responses matched their intention. A positive (+) score indicates that the participant is in favour of being physically active, while a negative (-) score shows that they are not. Prompts were used to aid those not able to answer the questions, and if after prompting they still could not answer the SPAIM, then the measure is administered to a proxy.

5.2.4. Phase two

Study one

Design: Construct Validity of the measure

Several types of validity can be measured when assessing the performance of a survey instrument, including face, content, criterion, and construct validity (Litwin, 1995). For the SPAIM, the author was interested in assessing its construct validity to establish the meaningfulness of the single-item question during use. To assess the construct validity of the SPAIM, the participants were surveyed to establish if the components of the measure, namely 30 minutes time duration and PA, were meaningful to them.

Eligibility

To be eligible for this sub-study, participants had to be able to communicate clearly either independently or with the use of assistive, or augmentative communication devices. This was established by applying the criteria for communication within the Leicestershire

Intellectual Disability tool questionnaire (Tyrer et al., 2008). Briefly, the question is described below:

Question - How clear is his/her speech? How easy is it to understand?

Descriptors

- *Not enough spontaneous speech to rate, or only meaningless echolalia*
- *Difficult to understand, even by close acquaintances. Impossible for strangers*
- *Easily understood by close acquaintances. Difficult for strangers*
- *Clear enough to be understood by anyone*

As a result, participants were selected based on whether their speech was clear enough to be understood by anyone, including strangers. The inclusion criteria were necessary because most people with intellectual disabilities, even at the mild or moderate end of the spectrum, will have some difficulty with communication (Tuffrey-Wijne and McEnhill, 2008), and Emerson et al. (2001), indicated that 80% of people with high IDS would never develop effective language.

Procedure

Timing was asked first as the question of time was likely to be more familiar to the participants than PA, therefore, easier to answer. To assess their understanding of time duration, they were asked a closed-ended question to identify a programme lasting 30 minutes from options consisting of three familiar TV shows lasting 3, 30 and 90 minutes respectively. To assess if the concept of being physically active was meaningful to them, they were asked an open-ended question inviting them to give examples of physical activities, by citing appropriate examples of PA (Appendix 8). Their responses were graded as 'understands' or 'did not understand'. Example(s) of PA was noted down and categorised as walking and other physical activities.

Study two

Design: Test-retest Reliability

Study two aimed to examine the test-retest reliability of the SPAIM by demonstrating how reproducible its data are over a period. Although there are other forms of reliability measures, including alternate forms, and internal consistency, the test-retest is the most

commonly used indicators of survey instrument's reliability (Litwin, 1995). The test-retest can show how stable a survey instrument is by having the same set of respondents complete the survey at two different time points. It can be used for a single-item measure as well as for a group of item questionnaire (Litwin, 1995).

For this test-retest study, 14-28 days' time was chosen for the retest, as it is unlikely that participants' physical activities would change between this period. This is to ensure that between the first and the repeated measure any changes observed can be attributed to the data rather than to changes in participants' PA.

Eligibility

For participants to be eligible for this sub study, they had to be available for a re-test between 14 and 28 days after the SPAIM was initially administered. Those that signalled that they would be available were invited to take part.

Procedure

The SPAIM was administered by the author, face-to-face to eligible participants or their family /carers (carer must have known them for at least 6months) to obtain information on their future PA intention. The measure was then repeated between 14 and 28 days after the initial one. It was administered to either the participants or their family/carer depending on who it was administered to initially. The author was blinded to their initial response. It was noted down who responded to the SPAIM and the type of prompt used.

5.2.5. Phase three

Design: Cross-sectional survey

This observational study was designed as a cross-sectional survey to measure PA levels and intentions across the intellectual disability spectrum in a representative sample of adults with intellectual disabilities. The SPAIM was administered at one point in time and only once to the respondents with the exception being those who took part in study 2 of phase two. Information was obtained from respondents who were either participants or a proxy, at a specific point in time. Details of the information are provided in 'procedure' below.

Eligibility

There was no eligibility criterion for this phase. All the adults with intellectual disabilities that were approached and who consented were eligible to take part with no exclusions applied.

Procedure

A survey (Appendix 9) was administered by the author face-to-face to each of the participants and their carers. It consisted of three sections: the first section was to obtain demographic and medical information; the second was to obtain information on current PA behaviour using the IPAQ-s (International Physical Activity Questionnaire, 2002; Craig et al., 2003; Lee et al., 2011); and the last section was to obtain information on future PA intention using the newly developed SPAIM. The use of IPAQ-s and its validity in adults with an intellectual disability population was described in detail in Chapters 3 and 4, and in Dairo, Collett and Dawes (2017a; 2017b).

Information about phase one to three studies

5.2.6. Sample size

For the item development in phase one, the author estimated a sample size of 8-12 to have participants from across the IDS. For both studies one and two (phase two), the required sample size was estimated to be at least 30 each. This was based on the central limit theorem (LaMorte, 2016). However, 35 participants were recruited to allow for dropouts and invalid data. For study three, the sample size was calculated using G* Power window software version 3.1.9.2. Downloaded from http://www.gpower.hhu.de/en.html. Alpha was set at the traditional significance level of 0.05 (Green, 1991). Power was set at 0.8, a value recommended by Cohen (1988) as appropriate for behavioural research. If one is willing to accept the power as 0.8 with a moderate effect size of 0.5, then the study would require 82 participants to test the correlation (if any) between PA intention and PA levels. This sample size is consistent with the calculation based on the rule of thumb, $N \geq 50 + 8m$, where 'N' is the sample size and 'm' is the number of factors (Green, 1991).

5.2.7. Data collection

For all participants, data on their characteristics were obtained for descriptive purposes. The data included demographic information (age, sex, residence type), current health history (if they had high blood pressure, high cholesterol levels, and diabetes), intellectual disability severities (whether mild/moderate/severe/profound), and the type of setting that they were recruited from (i.e. sports centre, day centres, intellectual disability community

events). All information was subjectively obtained first by asking the participants themselves and then from their family/carer as indicated. They were then assessed for their PA and their PA intention as described below. For participants in Phase 2, study one, additional information on the meaningfulness of 30 minutes time duration and PA was obtained as described in the study procedure. Likewise, additional follow-up SPAIM data were obtained as detailed in study two of Phase 2.

Physical Activity Assessment

The IPAQ-s was used to obtain information on self- or proxy-reported moderate and vigorous intensity PA, walking, and sedentary time (time spent in sitting or reclining positions). For the total amount of time spent engaged in each PA category per week, data within each item (i.e. vigorous intensity, moderate intensity, and walking minutes) were added up as per the official IPAQ-s guidelines (www.ipaq.ki.se., 2005). To estimate the MVPA intensity, vigorous intensity minutes/week was multiplied by two and added to the moderate intensity of PA/week. Any reported PA time exceeding three hours/day of activity in any category was treated as an outlier (i.e. they were capped at a maximum of three hours/day) in line with the IPAQ-s scoring protocol (www.ipaq.ki.se., 2005).

Physical Activity Intention Assessment

The author administered the newly developed SPAIM, face-to-face to all participants or their proxy (for those with communication difficulties) to obtain information on their future PA intention. The SPAIM collects information of PA intention, and as described in Phase 1, the intensity of participants PA intention is rated on a 5-point scale of -2 to +2 (i.e. intention can be negative, positive or neutral). The SPAIM's construct validity and test-retest reliability were examined in Phase 2.

The SPAIM was re-scaled from a 5-point to a 3-point scale to compare the reliability of the results of a 5-point rating scale of the measure, to that of a 3-point one, and to examine its sensitivity.

Variables

Independent variables: Age, sex, level of intellectual disability severities, race, type of residence, level of mobility, employment history, and PA intention.

Dependent variable: PA minutes/day and sedentary hours/day

5.2.8. Data analysis

A flowchart of the recruitment process was developed. Descriptive and frequency statistics were used to analyse age and other participants' characteristics (data collection setting, demographic and health information). Responses from the construct validity study were analysed using frequency statistics. Responses about PA intention were coded on a 5-point scale as -2= Very unlikely, -1= Unlikely, 0=Neutral, 1= likely, 2= Very likely. It was then re-coded to a 3-point scale as -1= Very unlikely/Unlikely, 0=Neutral, 1= likely/Very likely. The test-retest reliability of the SPAIM's 5 and 3-point scales was assessed using the Cohen's Kappa (k) and Spearman correlation coefficients (r_s). The median scores for both scales were compared using the Wilcoxon signed-rank test. Results were expressed as kappa and correlation coefficients for the Cohen's Kappa and Spearman Correlation coefficients respectively.

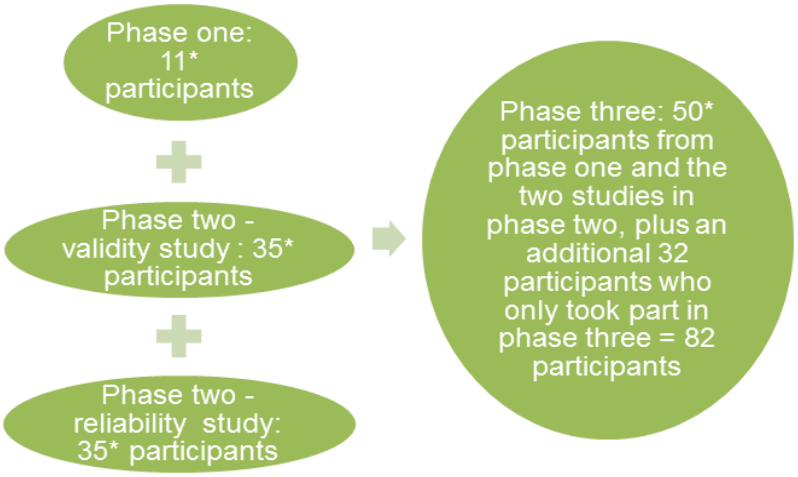
For the phase three data, statistical analysis was performed using regression models. For the first part of phase three, a multiple linear regression model was used to examine the combined associations between independent variables age, sex, type of residence, and high IDS, and the total volume of participants' PA in minutes/week. The multiple regression models were then repeated to examine the combined associations between the independent variables and the sedentary hours/day.
For the second part, simple linear regression analysis was run separately for each of the variables MVPA, walking minutes/week, overall PA minutes/week, and sedentary hours/day, to determine the relationship between the PA intention (as the predictor) and each of the variables. Results were expressed as regression coefficients representing the variation in the PA levels, which is explained by the regression model. All analyses were conducted using SPSS for Windows (version 22.0).

For all participants, frequency statistics were used to summarise total PA minutes/week, sedentary hours/day, and PA intention. Age groups (18-29; 30-44; 45-59, 60+) and intellectual severities (mild, moderate, severe, and profound) were compared for differences in PA levels using descriptive statistics (mean, standard deviation and frequency chart). A one-way ANOVA was used in analysing the group difference while Post Hoc analysis (Tukey) was done to determine the extent of the group difference (McDonald, 2014a). Analyses were done for within and between groups.

5.3. Results

5.3.1. Participants

Overall 82 out of 88 (93%) individuals that were approached agreed to take part. For the six individuals who did not take part, three had a profound ID, and although they had their carers with them, it could not be established whether they were interested or not. The other three did not give any reason for declining to take part. No one who wanted to participate was excluded from the study – see Figure 5.1 for the recruitment flow. Those that did not meet the eligibility criteria for either of the sub-studies in phase two took part in Phase three. Thirty-five individuals participated in each of the studies in phase two with 20 of those participants involved in both studies. Participants were aged 20 to 68 years (mean age of 36 (12.6) years). The descriptive data from the participants are presented in Table 5.1.



*Participants were in more than one study phase

Figure 5.1 Recruitment flow

5.3.2. Phase one

Participants

Of the total 82 participants, the first 11 recruited contributed to the development of the measure. They had mild-profound intellectual disabilities and were aged 28 to 68 years (mean age of 48 (11.4) years).

Table 5.1 Participants' characteristics (demographic and health information). Phase three, n=82

Participants' Characteristics		Count	%
Sex	Female	33	40%
	Male	49	60%
Race	Asian	4	5%
	Black	6	7%
	Mixed	4	5%
	White	68	83%
Intellectual Disabilities Severity	Mild	23	28%
	Moderate	26	32%
	Profound	17	20%
	Severe	16	20%
Employment	No	65	79%
	Voluntary	5	6%
	Yes	12	15%
Residence	Home	30	37%
	Supported living	52	63%
Mobility	Assistance required	9	11%
	Independent	42	51%
	Need assistance	7	9%
	Wheelchair	24	29%
High BP	No	48	59%
	Not Known	31	38%
	Yes	3	4%
High Cholesterol	No	44	54%
	Not Known	36	44%
	Yes	2	2%
Diabetes	No	63	77%
	Not Known	15	18%
	Yes	4	5%

5.3.3. Phase two

5.3.3.1. Study one - Construct Validity

Participants

Thirty-five adults with mild-profound intellectual disabilities aged 20 to 68 years (mean age of 39 (13) years) met the criteria for study one; therefore, they were selected to participate. Some of the participants in study one (n=5) had previously contributed to the questionnaire development in phase one.

Study 1: All 35 participants accurately identified time duration as well as understood PA. They were all able to provide at least one example of PA, without needing a proxy help. Their understanding of PA ranged from walking (most cited examples) to vigorous intensity physical activities such as horse riding. The examples that they cited for PA is presented in Figure 5.2.

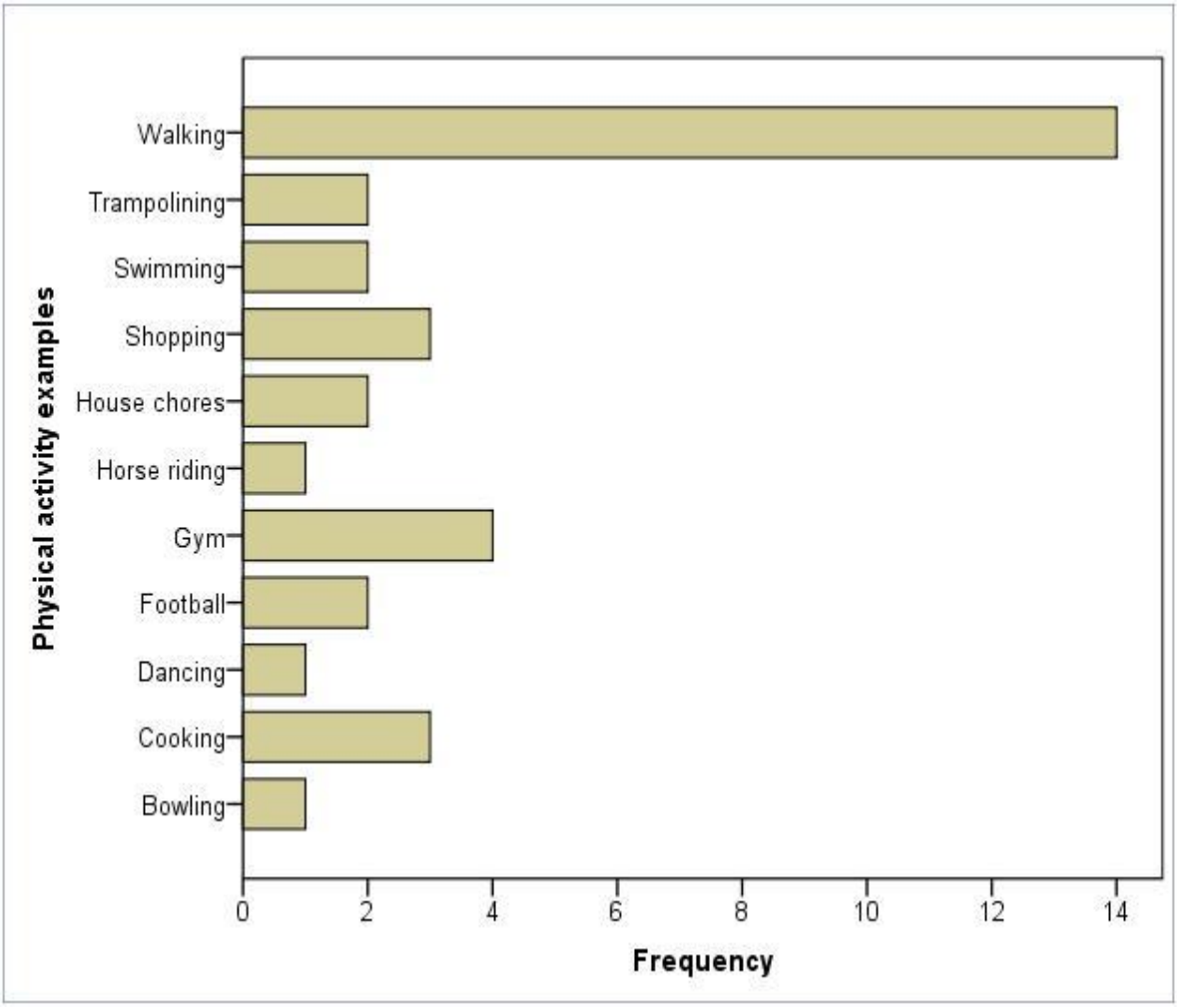


Figure 5.2 Descriptive summary of PA

5.3.3.2. Study two - Test-retest Reliability

Participants

Thirty-five participants that indicated availability for follow-up within two-four weeks of them undertaking the SPAIM were selected to take part in the test-retest reliability study. Some of these participants (n=20) had also met the inclusion criteria for study one. Therefore, they participated in both studies one and two, as well as contributing to the questionnaire development in phase one (n=5). Consequently, there were similarities in the demographics between the studies. The participants in this study were aged 20 to 68 years (mean age of 36 (13) years).

Response to SPAIM

We can see from Table 5.2 that of the 35 participants initially surveyed, 28 had a positive intention towards future PA, with 15 of them responding as likely and another 13 as very likely. Whereas for six participants, their PA intention was negative, with three unlikely and very unlikely respectively. Overall, one participant was neutral. Similarly, at two-to-four weeks' follow-up, the numbers of participants with positive, negative and neutral responses were the same as the initial survey, but the individual responses of the intensity of intention differed from the first survey to follow up as shown in Table 5.2. However, these differences were not significant as demonstrated by Cohen's analysis with a substantial agreement between the first and repeat survey, k= 0.70, p<0.001. Additionally, Spearman correlation coefficient showed a strong, positive correlation between first and repeated 5-point scale response, r_s =0.78, p<0.001.

Table 5.2 The cross-tabulation of PA intention at initial contact and at follow-up using the SPAIM 5 point-scale (n=35)

		SPAIM at follow-up*					
		-2	-1	0	1	2	Total
Initial SPAIM	-2	3	0	0	0	0	3
	-1	0	3	0	0	0	3
	0	0	0	1	0	0	1
	1	0	0	0	11	4	15
	2	0	0	0	3	10	13
Total		3	3	1	14	14	35

*Measure of Agreement with initial SPAIM, Kappa=0.699 p=0.000

Three participants needed prompts, with their carer or family's suggestion, the SPAIM was modified by replacing 'standing or moving around' with a specified PA that was specific to them. For one participant, it was 'dancing' and for the other two, 'walking'. The modification was noted, added to the standard procedure, and used at follow-up.

Five out of 35 participants needed a proxy respondent. Four out of the five participants that needed a proxy respondent had a different carer with them at follow-up; however, this did not affect their response to the SPAIM as their response at follow-up matched the initial SPAIM response.

Re-scaling

When the responses from the initial SPAIM from the 35 participants were re-scaled from a 5 to 3-point scale, the median score of the questionnaire was 0.28 scale points lower for the 3-point scale compared to the 5-point scale. This difference was statistically significant at $p<0.05$. However, when the responses from the five participants with proxy response were excluded from the analysis, re-scaling from 5- to 3-point scales, the overall median score of the questionnaire was 0.24 scale points lower for the 3-point scale compared to the 5-point scale. This difference was not statistically significant.

For the test-rest of the 3-point scale, at first survey, in the same way as the 5-point scale, 28, six, and one participants had a positive, negative, and neutral PA intention respectively (Table 5.3). However, there was no difference between the intensity responses at two-to-four weeks'. Thus, there was a perfect agreement and a perfect correlation between the first surveys compared to those at two-to-four weeks.

Table 5.3 The cross-tabulation of PA intention at initial contact and at follow-up using the SPAIM 3 point-scale (n=35)

		SPAIM at Follow Up			Total
		-1	0	1	
Initial SPAIM	-1	6	0	0	6
	0	0	1	0	1
	1	0	0	28	28
Total		6	1	28	35

5.3.4. Phase three

5.3.4.1. Participants

There were 82 participants recruited from different settings, namely leisure centres (n = 19, over five visits), day opportunity centres (n = 11, over three visits), sporting events (n =27, over five visits), and community learning disability events (n =25, over four visits).

The participants were aged 20 to 68 years (mean age of 36 (13) years). Their characteristics, including demographic and health information, are found in Table 5.1. They had mild to profound intellectual disabilities with approximately 40% of participants having a high severity (i.e. severe or profound ID). The majority (68%) lived in supported accommodation. More than a third of the participants said they did not know if they had high blood pressure or high cholesterol.

5.3.4.2. Physical Activity

Participants' PA was analysed using descriptive and frequency statistics as shown in Table 5.4 and Figure 5.3(a) respectively. By inspecting the data, 32 out of the 82 (39%) participants achieved 150 minutes of PA/week compared with 50 (61%) who did not. Therefore, fewer participants were active compared to those that were inactive. When the MVPA was considered without walking minutes/week, the number of active and inactive participants dropped to 11/82 (13%) and 71/82 (87%) respectively (Figure 5.4).

Table 5.4 Descriptive Statistics for PA minutes/week and sedentary hours/day

	Moderate-to vigorous-PA mins/week	Walking mins/week	Overall PA mins/week	Sedentary hours/day
No	82	82	82	79
Mean	77.60	165.04	242.63	7.06
Median	16.00	8.50	65.00	7.000
Mode	0	0	0	10.0
Std. Deviation	178.08	287.53	341.78	3.90
Minimum	0	0	0	1.0
Maximum	1080	1260	1260	14.0

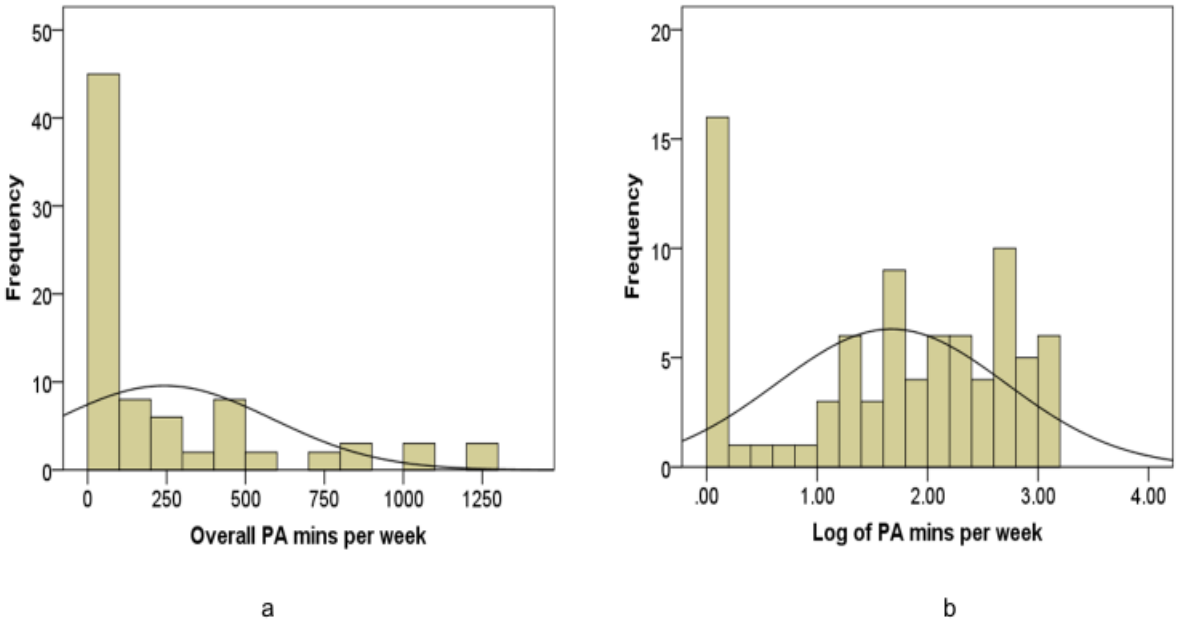


Figure 5.3 The actual overall PA minutes/week (moderate- to vigorous-PA and walking minutes) and Log of PA, n=82

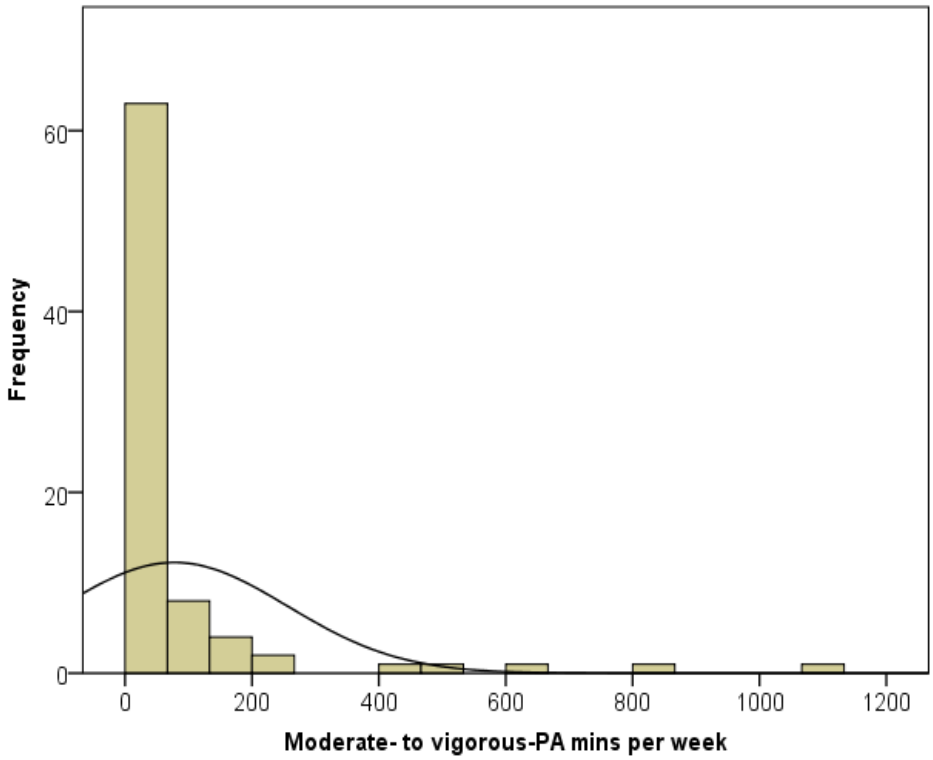


Figure 5.4 Moderate to vigorous PA minutes/week, n=82

The actual PA minutes/week was not normally distributed, therefore log of PA minutes/week was used for the analyses (Figure 5.3 (a and b)). The log of PA minutes/week, and the sedentary hours/day were compared between the different age groups, IDS, type of residence and sex, using descriptive and frequency statistics. One-way ANOVA showed there was a significant difference in PA minutes/week across the IDS ($F(3, 76) = 5.554$, $p = 0.002$). Post-hoc analysis revealed that PA minutes/week for participants with profound intellectual disabilities was significantly lower than those with mild or moderate severities, $p < 0.05$. The frequency statistics showed that PA varied across age groups. However, no inferential statistics could be done reliably because of the large differences between age group sizes. The trend for females was an increasing PA minutes/week across the age groups, while for males there was no consistent pattern (Figure 5.5).

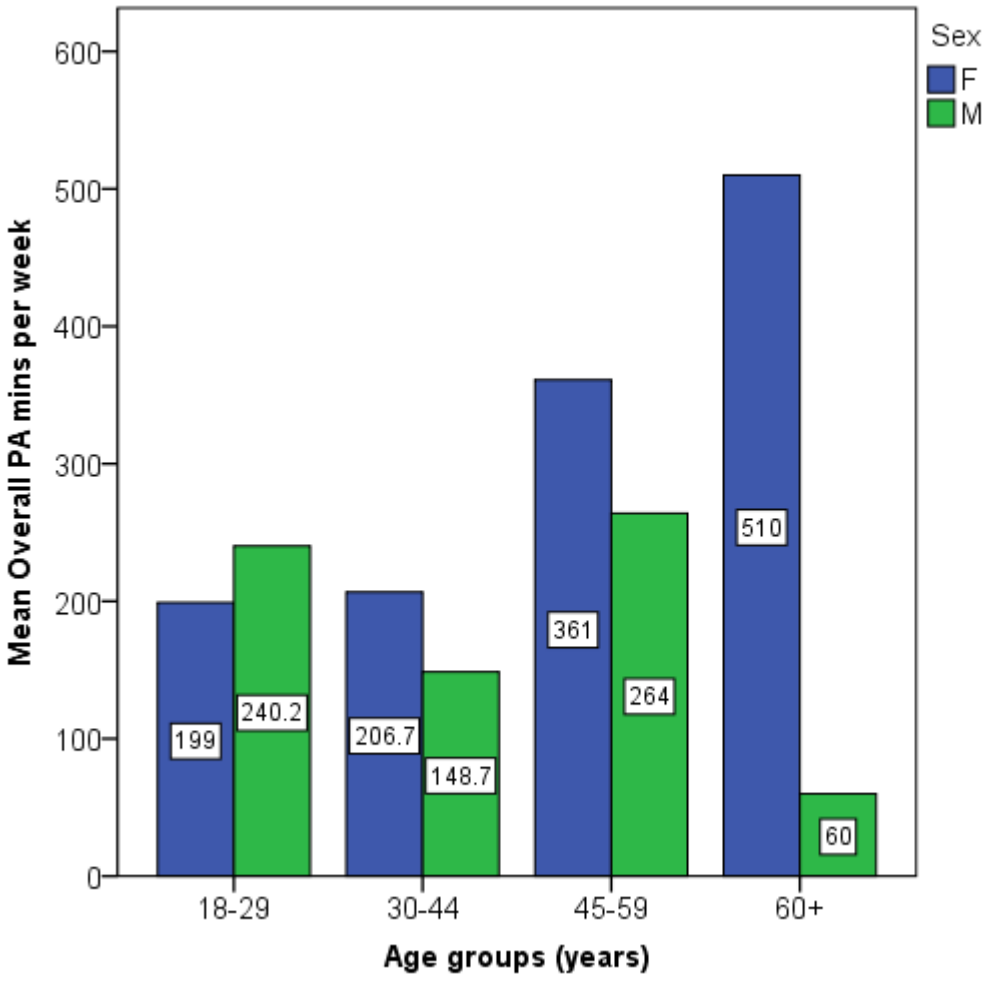


Figure 5.5 PA minutes/week by age groups and by sex, n=82

5.3.4.3. Sedentary hours per day

Sedentary behaviour data from the participants were also analysed using descriptive (Table 5.4) and frequency (Figure 5.6) statistics. There were sedentary hours/day data for 79 out of 82 participants. Two of the participants declined to say how long they spend sitting or lying down in the daytime, and one participant (mild intellectual disabilities and lives alone) could not estimate sitting hours even with prompt. The descriptive statistics showed that participants sit (or lie down) for a mean of 7 (3.9) hours/day ranging from 1-14 hours. The most frequently reported sedentary hours/day was 10 hours, approximately one in four (20/79) estimated their sedentary time to be 10 hours/day. More than half of the participants, 43/79 (54%) sit for more than 7 hours/day; 50/79 (63%) sit for >6 hours; 61/79 (77%) sit for >4 hours/day; and 65/79 (82%) sit for >3 hours/day (Figure 5.6).

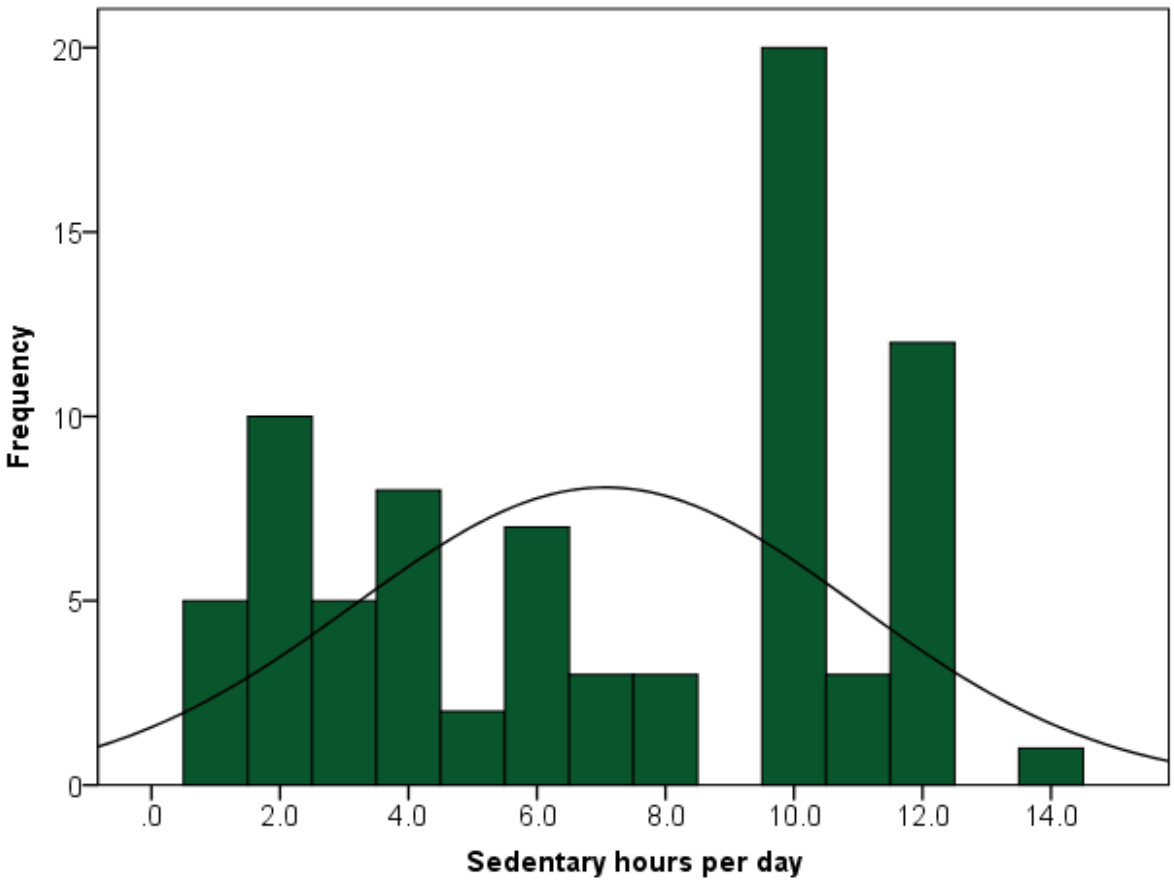


Figure 5.6 Sedentary hours/day, n=79

Like the PA data, sedentary hours/day was compared between IDS, age groups, residence, and sex, using descriptive and frequency statistics. The one-way ANOVA revealed a statistically significant difference in the sedentary hours/day between the different severities ($F(3,73) = 5.626$, $p = 0.002$). Post-hoc analysis revealed that the sedentary hours for participants with profound intellectual disabilities was significantly higher than those with mild or moderate severities by up to four hours/day, $p < 0.05$. Figure 5.7 shows the differences across IDS and sex. The frequency of the daily sedentary hours varied across the age groups and by sex, but the differences were not statistically significant.

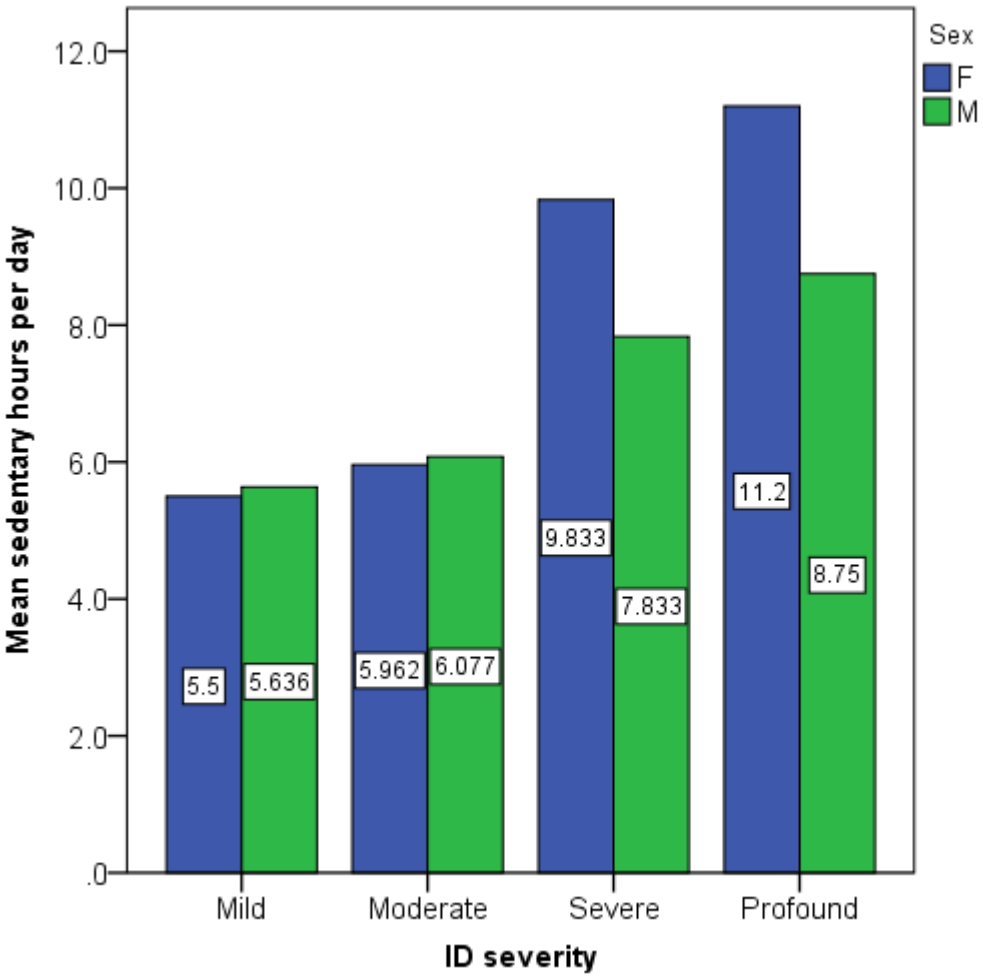


Figure 5.7 Differences in sedentary hours/day by IDS and by sex

5.3.4.4. Factors influencing physical activity

A multiple linear regression analysis was completed to examine the relationship between the participants PA minutes/week and predictor variables: age, sex, type of residence, and IDS. The regression equation was not significant. However, the coefficients show that

IDS have a significant effect on the variability in participants' PA minutes/week (Beta -0.28, $p<0.05$). In contrast, the other independent variables were not significant, and the type of residence had the highest p-value of all the predictor variables ($p=0.979$). Using a step-wise regression, the type of residence was removed from the equation. Consequently, the regression equation became significant ($R=0.35$, $p<0.05$). The results are presented in Table 5.5. Further step-wise regression made no significant difference to the model. Collinearity test between all the predictor variables was not significant (Durbin-Watson =2.2).

Table 5.5 Summary of the Multiple linear regression analysis for the variables predicting PA/week of adults with intellectual disabilities (n=74)[a]

ANOVA[b]			Coefficients[b]			
Df (regression, residual)	Mean Square (regression, residual)	F		B	Beta	t
3	332745.687	3.257*	(Constant)	312.336		1.448
71	102170.337		Age	3.480	.135	1.183
			Sex	34.455	.051	.447
			ID Severity	-190.882	-.276	-2.360*

Predictors: (Constant), age, sex, and IDS; [a]Incomplete data for eight participants; [b]Dependent Variable: % meeting PA guidelines; *significant at p value <0.05.

As well as the multiple regression, a simple linear regression analysis was performed for the independent variable IDS, and participants PA minutes/week. It revealed a significant linear relationship between the participants total PA minutes/week and the severity of ID. The results show that PA minutes/week could be predicted from IDS by the following formula: participants' PA minutes/week = -219.52x IDS + 525.9, $R = 0.32$. The regression model was significant, $p<0.01$ with an R^2 of 0.1. There was no significant relationship between participants PA minutes/week and the other predictor variables (i.e. age, sex, and whether they lived at home or in supported living).

A second multiple linear regression analysis was completed to examine the relationship between the participants' sedentary hours/day and the predictor variables. The regression model was significant [$F(4, 73) = 4.51$, $p<0.01$] with an Adjusted R^2 of 0.15. The analysis shows that among all predictive variables, the severity of the intellectual disability is the only variable that was significant with a Beta of 0.41 ($t_{(4)} = 3.68$, $p<0.001$). Therefore, a

1% increase in the proportion of participants with severe and profound intellectual disabilities had a relative contribution of approximately 0.41% on the regression equation when all the other factors were controlled for. Stepwise regression analysis made no significant difference to the regression model. Similar to the first regression analysis, the collinearity test between all the predictor variables was not significant (Durbin-Watson =2.05).

5.3.4.5. PA intention

Participants' intention to be active was analysed using frequency statistics as presented in Figure 5.8. Out of the 82 participants surveyed, 59 had a positive intention towards future PA, with 30 of them responding as likely and another 29 as very likely. Whereas for 15 participants, their PA intention was negative, with 11 unlikely and four very unlikely. Eight participants said that their PA intention was neutral.

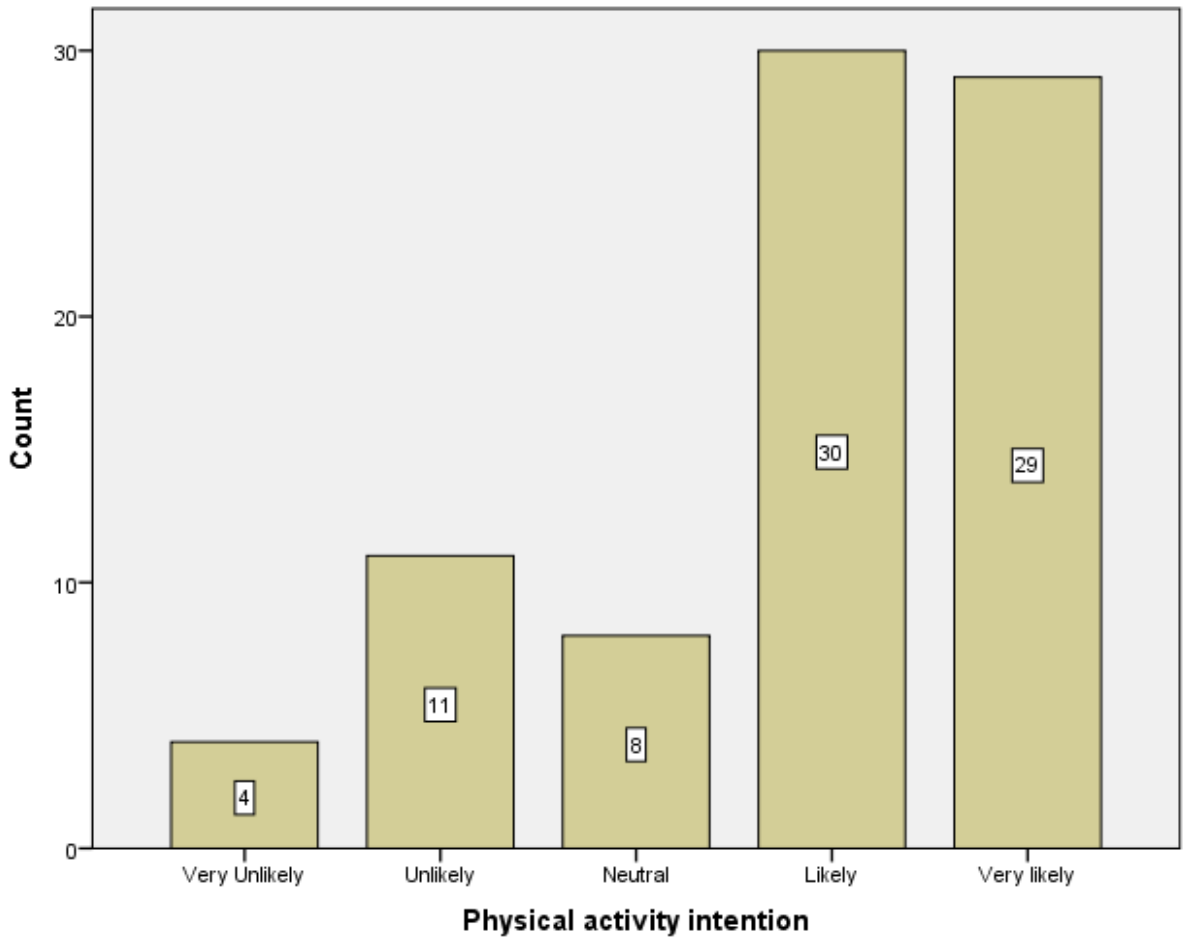


Figure 5.8 Bar chart showing PA intention measured with SPAIM, n=82

The SPAIM was administered to all participants, 11 of them needed prompts while eight required a proxy due to communication difficulties such as using sign language or customised communication device. Of those that required prompts, one participant did not understand 30 minutes time duration; hence their carer used TV soap duration to explain it. The other 10 participants that were prompted had the SPAIM question modified by replacing the phrase '… *do something that involves either standing or moving around*…' with specified PA as advised by their proxy. Those activities were: standing (x2), walking (x5), dancing (x2), and trampolining (x1).

A linear regression analysis was carried out to determine the relationship between PA intention and dependent variables: MVPA, walking time per week, overall PA minutes/week, and sedentary hours/day for the 82 participants. PA intention significantly predicted daily sedentary hours, Beta of -0.343, $t_{(1)} = -3.204$, $p<0.01$[14]. PA intention also explained a significant proportion of variance in the sedentary hours/day, $R^2 = 0.12$, $F(1, 77) = 10.27$, $p < .001$. However, there was no correlation between PA intention and moderate- to vigorous-PA minutes/week or walking minutes/week or the overall PA time/week (i.e. both MVPA and walking time), although the relationship between walking and PA intention tended towards significance at p= 0.08.

5.4. Discussion and Conclusions

5.4.1. Physical activity levels of adults with intellectual disabilities

This is the first study to measure PA levels of adults with intellectual disabilities across the intellectual disability spectrum using a subjective measure that was validated within an intellectual disability population. The results of this study confirmed low PA levels in adults with intellectual disabilities. Only 39% of participants were active, with participants spending an average of 78 minutes/week doing moderate- to vigorous-PA. This is against the backdrop of the local authority area where the participants were recruited; it is more active than the England average. The latest figures for Public health England (2017) showed that approximately 61% of adults in Oxfordshire are active compared to the England average of 57%. This suggests that other intellectual disabilities population in various parts of England might fare worse.

[14] The linear regression could be further analysed to show which category of PA intention influenced sedentary hours/day the most. However, the analysis would require an appropriately powered study as there would be three independent factors instead of one.

The participants in this study are not as active as the national average (Public Health England, 2017), or the global adult population, estimated at 77% (World Health Organisation, 2010). However, they are more active than the 9% observed in the systematic review of PA levels of adults with intellectual disabilities in Chapter 2. Furthermore, 39% of active participants fall within the range reported in the studies that were included in the review. Notably, the bigger studies in the review (studies with >50 sample size) observed a range of 0-27%. As the author acknowledged in Chapter 1, studies measuring PA levels in intellectual disabilities populations used different designs and methods making comparisons of result challenging. To compound this, not all studies would have excluded PA that lasted for less than a continuous bout of 10 minutes, which might have inflated their participants' PA minutes/week. This is expected as PAG guidelines stipulating activities should be in bouts of at least 10 mins is as recent as 2010 (World Health Organisation, 2010). Despite the differences in the percentage of participants achieving PAG in this study and those reported in other studies, as detailed in Chapter 2, there is a consensus that adults with intellectual disabilities are not as active as the wider adult population.

Recent global data on PA levels estimated that women are more inactive (33·9%) than men (27·9%) (Hallal et al., 2012). However, in this study, the author did not find significant differences between male and female PA minutes/week. Additionally, inactivity increases with age in all WHO regions, but that was not replicated in this study. Despite the trend for females showing an increase in PA minutes/week across the different age groups, there was no consistent pattern for males. Although a decrease in activity with advancing age, is known to have a strong biological basis (Ingram, 2000) the influence of other factors, particularly the severity of the intellectual disability may have eclipsed other lesser factors.

Some studies have examined PA in individuals with a long-term condition such as stroke and mental health issues (Butler and Evenson, 2014; Kruisdijk et al., 2017). Compared with PA data from controls in those studies, participants with a long-term condition had lower PA, but the difference is not large. For example, Butler and Evenson (2014) found that 17.9% of participants with stroke met weekly PAG compared with 25.0% of participants without stroke. This contrasts to the large difference found in the percentage of participants in this study that met PAG compared to the data for the wider population in the area where they were recruited.

5.4.1.1. Sedentary behaviour

With regards to sedentary behaviour, 82% of the participants spend >3 hours/day being sedentary, suggesting high sedentary behaviour among adults with intellectual disabilities. This finding is significant, in the U.S. Katzmarzyk and Lee (2012) demonstrated that population life expectancy would be two years higher if adults reduced their usual sitting to < 3 hours/day. Also, more than half of the participants in this study sit for seven or more hours daily, the level at which the risk of all-cause mortality increases significantly (Chau et al., 2013). What is more, one in four participants sits for 10 hours or more daily. Notably, 10 hours was the most frequently reported sedentary time. These findings are broadly consistent with the findings from a recent systematic review by Melville et al. (2017). In their study, they found that objectively assessed sedentary time in adults with intellectual disabilities ranged from approximately 9-11 hours/day, and it is higher than in adults without intellectual disabilities (Melville et al., 2017). The only study they found that reported a high sedentary value of approximately 19 hours/day (Finlayson, Turner and Granat, 2011) used an inclinometer, which may have inflated their results. Moreover, there are less than 19 waking hours in a day.

The high level of sedentary behaviour observed in this study is comparable to sedentary data obtained from individuals with other long-term conditions such as stroke patients (Butler and Evenson, 2014) and people with people with bipolar disorders (Vancampfort et al., 2016). It is also similar to sedentary data from older adults with limited mobility (Fitzgerald et al., 2015). However, it is higher than the sedentary hours/day found in the wider population. Hallal et al. (2012) analysed sedentary data from 66 countries, both of high and low income; they found that the proportion of adults spending four or more hours/day being sedentary is 41·5% (41·3–41·7). In the current study, that figure is higher as the author found that 77% of participants are sedentary for four or more hours/day. Equally important, Hallal et al. (2012) also found that although the sedentary hours/day vary greatly in WHO regions, it was similar in both sexes, and in adults aged 15–59 years. However, the proportion, spending four hours or more per day being sedentary increases in those aged 60 years or more. In the current study like the global findings, age and sex did not significantly affect sedentary hours/day. Likewise, sedentary hours/day was highest in those aged 60 years and over with a mean time of 7.7 (range from 7-10) hours compared to the mean for all participants, which was 7.1 (range 7-13) hours/day.

5.4.1.2. Intellectual disabilities severity and physical activity levels

In addition to confirming low PA levels in this population, this study also found that the severity of intellectual disabilities is an important predictor of PA. Linear regressions

between predictor variables: age, sex, residence, and IDS showed that severity alone significantly influenced the participants PA minutes/day and sedentary hours/day. High severity correlated significantly to a low PA, and high sedentary behaviour. It also explained a significant proportion of variance in the PA minutes/day and sedentary hours/day observed. Similarly, in Chapter 2, it was found that the IDS is the strongest predictor of the number of participants achieving PA guidelines. Remarkably, in contrast to the results from this study, in Chapter 2 the other predictor variables, i.e., living in care, sex, and age were independently significantly correlated with the number of participants achieving PA guidelines. Several reasons may explain this difference. To begin with, the systematic review consisted of over 3,000 participants. While a power calculation for the current study indicated 82 participants, because of incomplete data, the regression model was done with less than 82 participants, which may have affected the results. Besides, findings from the current study should be in the context that the participants were across the spectrum (i.e. mild to profound), in contrast to the data from the systematic review in Chapter 2 where most of the participants were in the mild or moderate range of IDS (only 4% had profound ID). Another difference between this study and the systematic review is the participant's residence. In the systematic review, participants lived in residential-homes as well as supervised care, with family, and alone. Whereas in this study none of the participants lived in a residential home, they lived either at home or in supported living, which is like living with family.

5.4.2. Development of the single-item PA measure

A new measure, the SPAIM, was developed to measure the PA intention of adults with intellectual disabilities across the spectrum. Normally, there are several steps involved in the development and analysis of a measure or questionnaire (Hinkin, Tracey and Enz, 1997; Macnamara and Collins, 2011). The various steps were described in detail by Hinkin et al. (1997). Briefly, the various stages involved starts from creating the items in the measure, right through to factor analysis, and investigating replicability with a new data set. However, not all these steps are required for a single-item measure like the SPAIM. Despite that, research evidence has shown that single-item measures have acceptable psychometric properties (Milton, Bull and Bauman, 2011; Silsbury, Goldsmith and Rushton, 2015). Likewise, the author found that the SPAIM's content was meaningful to adults with intellectual disabilities, and its data are a reliable measure of intention over time. Additionally, it was observed that the initial 5-point scale of the SPAIM was more sensitive compared to the 3-point scale, but it was less stable. Both the 5-points and 3-point scales were a reliable measure of PA intention.

The SPAIM is quick, simple, and easy to use. Important characteristics that make a subjective measure desirable (Tudor-Locke and Myers, 2001). The author observed that most participants could answer the one-item question independently. It was used alongside the IPAQ-s, signifying that it can be easily incorporated into existing PA measurements.

5.4.2.1. SPAIM design

The SPAIM is a researcher-administered single-item question that rates individual's intention to be active, in three directions of positive, negative and neutral. Nardi (2006) argued that feelings cannot simply be considered in a dichotomous way like "yes" or "no". He suggests that while we may have several clear preferences and opinions, we frequently feel strongly about them. This notion was described as the intensity of belief by Nola (2007), who observes that for the same person, belief and its intensity can change over time. Furthermore, he found that different people can share the same opinion, but with different intensities. For these reasons, intensities of feelings or preferences are measured. A commonly used intensity scale is one devised by Rensis Likert in 1932 (Likert, 1932). Typically, it uses 1 to 5 rating scale where one is "strongly agree", two is "somewhat agree", three is "neutral", four is "somewhat disagree", and five is "strongly disagree". The intensity of the Likert scale could also be rated in three directions of positive, negative and neutral to measure the range of positive to negative opinions. Some researchers mimic the original Likert format, but with 3-, 7- or even 10-point scales. The SPAIM was made as a 5-point scale similar to the Likert scale, to keep it simple and also because a 7-point scale has been shown to reach the upper limit of the Likert scale's reliability (Allen and Seaman, 2007).

5.4.2.2. Psychometric Properties of the SPAIM

Adults with intellectual disabilities found the main concepts of the SPAIM meaningful, as evidenced by the results of the construct validity study. Past research on similar self-report PA surveys tends to investigate criterion or convergent validity (Li, Carlson and Holm, 2000; Milton, Bull and Bauman, 2011; Milton, Clemes and Bull, 2013). However, those are not appropriate for the SPAIM. The results of the validity study showed that the main concepts of the measure (i.e. 30 minutes time duration and PA) were meaningful to participants. It is possible that the results were enhanced by ensuring that all the participants for the construct validity study could communicate effectively. Though this could have a bearing on its external validity, communication is important, to enable the author to assess whether the components of the questionnaire were meaningful to individuals with an intellectual disability. Not only were the concepts meaningful to the participants, but also, they found the validity questions easy to answer as none of them

required proxy help. Again, probably because they could communicate independently, but it is also likely that it is because the choices that they were offered to check the meaningfulness of the SPAIM's question were based on real-life scenarios. For instance, to check that the 30 minutes time duration was meaningful to the participants, they had a choice of familiar TV programme of varying durations of which one of them lasted for 30 minutes. By offering them choices based on familiar concepts, they could relate easily to it. Therefore, the author recommends that when using the SPAIM, everyday things such as popular television programme could be used as prompts for individuals who are struggling to make sense of what 30 minutes duration is.

Reliability of response over time

The SPAIM was found to be a reliable measure of PA intention. Although this is the first time such a measure has been used in adults with intellectual disabilities population, other studies have examined the reliability of single-item measures in other populations. In a study examining the reliability and validity of a single-item measure of 'usual PA' of 188 perimenopausal women, Li and colleagues (Li, Carlson and Holm, 2000) found that the single-item tool was a reliable (r=0.88) measure in that population. Another study that used a self-reported single-response PA item to assess adult participants' PA behaviours demonstrated significant test-retest reliability (r= 0.81) with a time frame of approximately seven days (Jackson et al., 2007).

Most of the participants in this study could answer the SPAIM's question independently, but some with communication difficulties required a proxy. Within an intellectual disability population, the use of proxy- or self-report survey is commonplace (Melville et al., 2017). For those participants with proxy-respondents, their responses were consistent at the test-retest follow-up, even when there was a different carer. Consistency in carer's response is important, especially if the SPAIM is to be used with adults with profound and multiple intellectual disabilities, the majority of whom might need a proxy.

As far as the accuracy of a proxy's response is concerned, evidence varies. For example, in Chapter 4 (also in Dairo et al. (2017)), the author investigated the agreement between carers' and participants' recall of PA over the previous seven days, and that of objectively measured seven-day accelerometer data. Reliability was found to be good for a broad indicator of PA level (k=0.66) where the variable was dichotomous, that is, does the individual meet the PA guidelines or not. However, the agreement was less when considering the actual reported PA minutes/day, with as many carers underestimating as overestimates PA minutes/day. Similarly, Temple and Walkey (2003) examined the concurrence between proxy generated estimates of PA via diary recordings and

accelerometer produced estimates of PA for 37 adults with intellectual disabilities. They found the interclass correlation coefficient between the two data to be 0.78, suggesting that proxy recording of PA behaviour provides meaningful data. On the other hand, other studies have found proxy responses to be different from that of participants (Heller, Hsieh and Rimmer, 2002; Melville et al., 2017). While it is difficult to make direct comparisons between the studies that found agreements between proxy and participants' response and those studies that did not, primarily because of differences in their design, the author found in Chapter 4, as well as other studies have shown that where the participants are well known to the proxies, it improves the reliability of the proxy response (Magaziner et al., 1996; Magaziner et al., 1997). The proxy respondents in this study were either family or carers who know the participant well.

5.4.3. Physical activity levels and intentions of adults with intellectual disabilities

The other important finding of this current study is that it shows for the first time that the PA intention of adults with intellectual disabilities is a significant predictor of their sedentary behaviour. Although the finding of a linear relationship between intention and sedentary behaviour is new, Temple (2007) found that the best predictive variables for the number of steps/day for adults with intellectual disabilities, were barriers to PA and preference for sedentary behaviour. The association between PA behaviour and intention is important given the prevalence of high level of sedentary behaviour and high physical inactivity in the intellectual disabilities population. As discussed in the introductory section of this chapter, TPB, which is one of the most commonly used models for changing behaviours suggests that the main determinant of behaviour is the person's intention to perform a specific behaviour (Ajzen and Fishbein, 1980; Ajzen, 1991). In the wider population, the understanding of intention had been used to change different health behaviours, including diet and smoking cessation (Schifter and Ajzen, 1985; Norman, Conner and Bell, 1999).

Of equal importance is the relationship between PA intention and PA. The author examined whether the PA intention could be a factor in how active people are. There was no correlation between PA intention and moderate to vigorous PA minutes/week or walking minutes/week or the overall PA minutes/week. This result is important because it shows that regardless that most of the participants in the current study were inactive, they may be positively disposed towards being active as supported by the high positive SPAIM's score. This suggests that the participants may want to be active irrespective of their current PA levels, indicating that although they have a positive intention to be active,

there are other factors preventing adults with intellectual disabilities from doing it. Future studies could examine their capability to be active and PA opportunity for those who intend to be active. Such a study could be modelled like the COM-B framework (Michie, van Stralen and West, 2011; Van Aerde, 2015).

5.4.4. Strengths and Limitations

5.4.4.1. External validity

Adults with intellectual disabilities are a difficult population to access (Bodde and Seo, 2009; Dairo, Collett and Dawes, 2017a). Consequently, a convenience sampling method was used for pragmatic reasons, recruiting from activity centres and events attended by adults with intellectual disabilities. Although this may have increased the likelihood of recruitment bias towards individuals with social support, and those who are more able, therefore, likely to be more active, representativeness was ensured by approaching an unselected sample of consecutive individuals. Remarkably, there was a very high recruitment rate of 93%, which is much higher than in the other two studies with a similar design to this one. Those studies' response rates were around 60%, despite offering incentives for enrolling in their study (McGuire, Daly and Smyth, 2007; Finlayson et al., 2009). It is likely that the simplicity of both the IPAQ-s and SPAIM encouraged participation in this study, as almost all the people approached agreed to take part. Moreover, there was no one excluded from the study, indicating that the results can be generalised to the population the sample was recruited. This was further evidenced by the fact that participants were recruited from across the spectrum (i.e. mild to profound), in contrast to the majority of PA research where most exclude individuals with severe to profound IDS (Dairo et al., 2016).

5.4.4.2. Researcher-administered survey

Another strength of this study is the survey being researcher-administered. Although this could increase the likelihood of the researcher influencing the response, in this case, it is unlikely. Researcher administering IPAQ-s is well documented, and the SPAIM has a set of five outcomes from which respondents could choose. An alternative method of administering questionnaire is through the post. Postal self-administered questionnaire is one the most common survey methods, but their low response rate (about 30%) is well documented (Nardi, 2006). Non-response to postal questionnaires reduces the effective sample size and can introduce bias (Armstrong, White and Saracci, 1995). Moreover, as the SPAIM is a new measure, and experts recommended the use of prompts, by administering the measure face-to-face, the researcher could determine how best the prompts work.

5.4.4.3. Measurement of physical activity levels and development of SPAIM

The other and possibly the major strength of this study is the measurement of PA and sedentary behaviour across the full spectrum of IDS, as well as incorporating the assessment of the intention to be active. The development of SPAIM is promising; however, more research is needed to validate it in diverse groups (e.g., those living in residential-homes and individuals whose first language is not English) and to examine the relationship between the various categories of intention and actual behaviour. For all that, the SPAIM offers a way to assess the PA intention of adults with intellectual disabilities. Participants' contribution to its development is remarkable. Although individuals with intellectual disabilities are the experts on their own experiences (Messent, Cooke and Long, 1999), there is evidence that they are expected to be more compliant than those without disabilities (Saaltink et al., 2012). Every effort was made to include adults with intellectual disabilities in the SPAIM's development to allow them to directly relay their feedback on what they thought of the measure, which is of immense value to the measure and individuals with intellectual disabilities. Saaltink et al. (2012) found that although young people with intellectual disabilities make fewer independent decisions about their lives than their typically developing peers, support in decision making can enable both increased protection and independence.

Equally important to the SPAIM design is the use of a closed question. Although this is a potential source of bias (Nardi, 2006), it gave respondents standardised answer to select from, therefore, making it easier and quicker for them to complete. This was evident in the consistency of the responses obtained at follow-up. With the 5-point scale SPAIM, there was a 78% correlation between the first and repeat responses, which increased to 100% following re-scaled to a 3-point scale.

5.4.5. Implications for future research

- The IPAQ-s could be used clinically and in research to measure PA when the outcome is dichotomised into met or did not meet PAG, and to measure the sedentary behaviour of adults with intellectual disabilities. Future studies could examine the reliability of the IPAQ-s in measuring daily PA of adults with intellectual disabilities and how this compares with weekly volume of PA.
- Individuals with high IDS are most at risk of low PA levels. Thus, researchers should look for evidence of good practice, which encourages participation of those with more profound intellectual disabilities.
- Proxy-responses to both the IPAQ-s and SPAIM were acceptable, possibly because the participants are well known to their proxies. Hence, the author

recommends that when the IPAQ-s or SPAIM is administered to a proxy, they should have known the individual for at least six months.

- The SPAIM needs more research to validate it in diverse groups and to examine the relationship between the various categories of intention and actual behaviour. Furthermore, there was a low number of 'neutral' response to the SPAIM. It is unclear whether this meant that participants did not know, or they did not mind. Future studies could explore the reasons for neutrality as well as the reasons for negative intention.
- The SPAIM could be used as a 3-point scale clinically as it might be quicker than the 5-point one, however, for research purposes the author recommends the 5-point scale as it appears more sensitive.

5.5. Conclusions

This study aimed to establish PA levels of adults with intellectual disabilities, and to develop a measure to further our understanding of their PA intention. The IPAQ-s was used in a representative sample of adults with intellectual disabilities, and it confirmed low PA and high sedentary behaviour in this population. It also indicated that the IDS is a major factor influencing whether participants are active or not. To increase PA and reduce time spent being sedentary, the use of a standardised PA measure like the IPAQ-s needs to be implemented broadly and repeatedly. IPAQ-s is already in use in the wider population, and the author anticipates that the findings from this study will further its use in people with intellectual disabilities. The use of a standardised measure is important to enable data comparison between PA studies and to understand which intervention strategies work for adults with intellectual disabilities. Furthermore, the PA and sedentary data from this study provide information on the pattern of PA levels across the intellectual disability spectrum, which is necessary to identify and target those who are most at risk of inactivity.

The development of SPAIM and the studies of its psychometric properties show promise for future studies of PA levels and intervention to change behaviour in adults with intellectual disabilities. However, more work is needed to validate its use in another group of respondents, such as those living in residential-homes and non-English speakers to determine the generalisability of these results. More research is also needed to investigate its predictive properties. Nonetheless, the results from this study suggest that it could be incorporated into IPAQ-s measurements. This could be useful for an intervention or a

health promotion programme. Finally, the SPAIM was found to predict sedentary behaviour with those that were highly sedentary more likely to have a negative intention towards PA - adding to the evidence that reducing sedentary hours should be a primary target for public health efforts in this population. These results could have implications for identifying those who will most likely take part in a PA intervention programme, as well as identify those in need of health promotion. Both of which are critical for improving the low levels of PA and high sedentary behaviour observed in this population.

Chapter 6. General Discussion

6.1. Summary

In this concluding chapter, the author will discuss the overall interpretations drawn from all the studies within this PhD thesis. The PA levels of adults with intellectual disabilities and its measurements are summarised, as well as some of the challenges to achieving improved PA levels. This will be followed by recommendations for future studies and how the findings from this PhD study could contribute to future PA intervention and health promotion in adults with intellectual disabilities population.

6.2. The physical activity levels of adults with intellectual disabilities and its measurements

The first study of this PhD research revealed that existing research observed low PA levels in adults with intellectual disabilities, but discovered that the data was informed by limited sampling and recruitment bias towards individuals with mild to moderate ID. Therefore, a feasibility study was done, which established for the first time, that it was possible to measure PA across the intellectual disabilities spectrum using existing measures – an accelerometer and the IPAQ-s. Next, a concurrent validation study between the two PA measures, found a substantial agreement (k= 0.6, p < .05) between the accelerometer and the IPAQ-s data in identifying participants who achieved the PA guidelines, as well as a positive correlation (r = 0.50, p = 0.04) between the measures in estimating sedentary hours/day. This means clinicians and researchers could use either an accelerometer or the IPAQ-s for PA measurement depending on the desired outcome. While the former may be more appropriate for daily measurements of PA (Chen and Bassett, 2005; Esliger et al., 2011; McGarty, Penpraze and Melville, 2015), the latter has a wider reach and is more accessible, and does not require any special training (International Physical Activity Questionnaire, 2002; Craig et al., 2003; Lee et al., 2011). Moreover, the IPAQ-s could also be used in epidemiological studies for collecting PA data for adults with intellectual disabilities, as well as by health policy makers who are interested in their PA trends. While the data from this PhD study does not evidence the reliability of the IPAQ-s for daily PA data, by being able to identify those that are active, it will make PA measurements more accessible and the routine assessment of PA possible.

In addition to the findings that IPAQ-s can measure PA levels in this population. Another original finding was the reluctance of intellectual disabilities home managers to engage

with PA research. The health disparities experienced by adults with intellectual disabilities are well documented (Krahn, Hammond and Turner, 2006; Emerson et al., 2014; Heslop et al., 2014), if that is to change, then examples of practice that promotes engagement with research in those living in residential or care homes, should be practised more widely. A good example is the ethics approval procedure in the Netherlands, which was discussed in Chapter 2. Briefly, board of residential facilities is involved in the research process, including ethics (Waninge et al., 2013; van der Putten et al., 2016). Countries wishing to do this might need to review their research governance policies.

6.2.1. Changing PA behaviour of adults with intellectual disabilities

The other major finding from this PhD is that it confirmed low PA and high sedentary behaviour in adults with intellectual disabilities across the spectrum. There is a need to change this PA behaviour. Changing PA behaviour in any population would achieve health benefits, especially in those who have low activity levels (Kyu et al., 2016; Public Health England, 2016). Moreover, increasing PA will reduce health care costs (Allender et al., 2007) and costs to the society in general (UKactive, 2014) . It has also been suggested that in people with intellectual disabilities, secondary health conditions can be lowered by increasing PA (Traci et al. 2002). Generally, adults who engage in less than 30 minutes of activity per week will produce the greatest reduction in chronic disease (Chief Medical Officer, 2011). Although the UK Chief Medical Officers' (2011) guidelines on the frequency and type of PA that provides the level at which health benefits are achieved across a wide range of conditions, is a minimum of 150 minutes/week of at least moderate intensity PA (or its equivalent), there is evidence that health benefits could be achieved by carrying out 10 minutes of brisk walking per day for 7 days (Murphy et al., 2007; Murtagh et al., 2015). Further research of PA in adults with intellectual disabilities could investigate how walking may be increased in this group. Such work could focus on exploring identical opportunities for those with lower limb mobility impairments, as this could inhibit walking (Public Health England, 2016).

Not only do individuals with intellectual disabilities have physical impairments that may limit their mobility (Harris, 2006; Pratt and Greydanus, 2007), but they also have cognitive impairment that increases their reliance on others, to either access PA facilities or actual assistance to be active (Bodde & Seo, 2009; Temple & Walkley, 2007). Other reasons may also stop or limit individuals with an intellectual disability from going out and assessing PA opportunities. Such factors include: not having enough money or means to pay for facilities or transport (Hawkins and Look, 2006; Temple and Walkley, 2007; Emerson and Parish, 2010); paid carers' preferences with respect to PA (Cartwright et al., 2017); physiological reasons that may limit movements (Dodd and Shield, 2005); and the

severity of intellectual disabilities (Dairo et al., 2016). It is important not only to address how adults with intellectual disabilities could go out more but equally, to explore alternative opportunities within the home. A recent study found that going out independently was significantly correlated to PA levels (Stancliffe and Anderson, 2017). Thus, the author recommends that future PA studies focus on intervention to reduce inactivity within the home or day centres. The author proposes that such studies use existing technology, for example, the Wii to encourage individuals with intellectual disabilities to be more active, and reduce sedentary behaviour.

Within the current literature, and the health care policy of the UK government, there are no specific recommendations to tackle the inactivity in people with intellectual disabilities. Despite the health gains from increasing PA and the likely cost savings, adults with intellectual disabilities seem to have been left behind when it comes to initiatives targeting physical inactivity. This is evident from the recent figures from Sport England (2016), which shows an increase in PA, among sectors of the community who were previously relatively inactive (women, people from Black, Asian and ethnic minority backgrounds, and young adults). However, those improvements in PA did not extend to those with disabilities (Sport England, 2016). To reduce health inequalities faced by adults with intellectual disabilities, PA intervention could help. The findings from this PhD research will add to the development of an appropriate intervention for this vulnerable group of people. The results from these studies could influence all the stages of the intervention. It will inform the appropriate recruitment strategy to ensure a representative sample; the choice of PA measurement that is usable across the spectrum for risk factor identification, and evaluating PA intervention; and the choice of PA intervention itself. Importantly, the SPAIM that was developed as part of this thesis demonstrates that there is a willingness for changing PA behaviour in this population. Providing a useful insight into their intention, which could be used for behavioural intervention as well as identifying those most likely to take part in a PA intervention. The SPAIM could also help in identifying those that might benefit from a health promotion programme, as well as contributing to behaviour change. With further development, the concept of SPAIM might inform ways of changing other unhealthy behaviours, just like understanding intention had helped in the wider population for changing health behaviours such as weight loss (Schifter and Ajzen, 1985) and smoking cessation (Norman, Conner and Bell, 1999)

6.3. PhD Study limitations

Throughout this PhD work, limitations of the four studies have been highlighted. One of the major objectives of this PhD research was to establish the PA levels of adults with intellectual disabilities, including those that are profoundly disabled. The PA measuring tool used in the final study, the IPAQ-s, is designed for people who can walk. While there is evidence that individuals with intellectual disabilities can have motor impairments that limit their mobility (Harris, 2006; Pratt and Greydanus, 2007), there is a section of the IPAQ-s that measures sedentary behaviour, which applies to all, irrespective of mobility status. To that end, no one was excluded from the studies based on their movement or lack of it. A descriptive analysis of participants' mobility status was provided in the relevant Chapters. Another limitation was that participants were recruited from local authorities in the South of England – Buckinghamshire and Oxfordshire. These two counties are one of the most affluent in the UK, and they have a higher number of active residents compared to the national average (Public Health England, 2017). For all that, there are pockets of deprivation within these counties, and the recruitment method ensured that the sample was representative. Therefore, it is likely that the participants in this research would be representative of the national average in respect of PA levels.

Finally, although previous researches in this population point to lack of regular PA, indicating that an intervention study would have been beneficial. However, due to time and resource constraints, this PhD research did not include an intervention. Nonetheless, it established the PA levels, as well as discovered an effective way to use an existing PA measure for adults with intellectual disabilities. It also developed an assessment tool for PA intention. These findings could inform future intervention and health promotion studies, and measurements of PA.

6.4. Final Remarks

The use of IPAQ-s as opposed to the direct method of PA measurement, allowed for a greater participation of adults with intellectual disabilities in the PA measurements, in spite of the barriers posed by gatekeepers. Consequently, the findings of this thesis have better external validity compared to previous PA studies, which were limited to a highly selected group, with mostly mild to moderate intellectual disabilities. The measurement of PA across the spectrum in a representative sample suggests that PA levels are low among adults with intellectual disabilities, and that the severity of the intellectual disability is the variable that most influence PA levels. The finding that the amount of time spent being sedentary correlates significantly to a negative PA intention, irrespective of whether they were active or inactive, suggests that sedentary behaviour is a problem in this population.

Fortunately, their overwhelmingly positive intention towards PA indicates that there is a readiness to change PA behaviour, an insight that has never been reported or studied. The author recommends based on the results of this PhD thesis, that intervention studies aimed at reducing sedentary behaviour are needed urgently in this group. The highly sedentary behaviour reported, and its relationship with PA intention indicate that reducing sedentary hours/day could be a target for public health prevention efforts in this population.

Word count 50771

References

Agiovlasitis, S., *et al.* (2011) 'Metabolic rate and accelerometer output during walking in people with Down syndrome', *Medicine and science in sports and exercise,* 43(7), pp. 1322. doi: 10.1249/MSS.0b013e31820936c4.

Ainsworth, B. E., *et al.* (2011) '2011 Compendium of Physical Activities: a second update of codes and MET values', *Medicine and science in sports and exercise,* 43(8), pp. 1575. doi: 10.1249/MSS.0b013e31821ece12.

Ajzen, I. (1991) 'The Theory of Planned Behavior', *Organ Behav Hum Decis Process,* 50. doi: 10.1016/0749-5978(91)90020-t.

Ajzen, I. and Fishbein, M. (1980) *Understanding attitudes and predicting social behaviour.* Englewood Cliffs, New Jersey: Prentice-Hall.

Ajzen, I. and Fishbein, M. (2001) 'Attitude and the Attitude-Behavior Relation: Reasoned and Automatic Processes', in Stroebe, W. & Hewstone, M. (eds.) *European Review of Social Psychology*. New York: Sons.

Allen, I. E. and Seaman, C. A. (2007) 'Likert scales and data analyses', *Quality progress,* 40(7), pp. 64.

Allender, S., *et al.* (2007) 'The burden of physical activity-related ill health in the UK', *J Epidemiol Community Health,* 61(4), pp. 344-8. doi: 10.1136/jech.2006.050807.

American Psychiatric Association (2000) *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR).* 4th Edition edn.: American Psychiatric Association. DSM Library.

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders : DSM-5.* Fifth edition. edn.: Washington, D.C. : American Psychiatric Publishing. DSM-5.

Armstrong, B., White, E. and Saracci, R. (1995) *Principles of exposure measurement in epidemiology. Monographs in epidemiology and biostatistics* New York: Oxford University Press.

Arora, A., Cummings, L. and Crome, P. (2016) 'Physician-facilitated designation of proxy decision maker', *Israel Journal of Health Policy Research,* 5. doi: 10.1186/s13584-016-0084-5.

Australian Government Department of Health (2014) *Australia's Physical Activity and Sedentary Behaviour Guidelines*. Available at: http://www.health.gov.au/internet/main/publishing.nsf/content/health-pubhlth-strateg-phys-act-guidelines#apaadult (Accessed: 21 September 2015).

Bandura, A. (1994) 'Self-efficacy', *In V. S. Ramachaudran (Ed.), Encyclopedia of human behavior* New York Academic Press. (Reprinted in H. Friedman [Ed.], Encyclopedia of mental health. San Diego: Academic Press, 1998), pp. 71-81.

Barnes, T. L., *et al.* (2013) 'Physical activity in a large sample of adults with intellectual disabilities', *Journal Of Physical Activity & Health,* 10(7), pp. 1048-1056.

Bassett, D. R. (2000) 'Validity and reliability issues in objective monitoring of physical activity', *Res Q Exerc Sport,* 71(2 Suppl), pp. S30-6.

Bellet, R. N., Adams, L. and Morris, N. R. (2012) 'The 6- minute walk test in outpatient cardiac rehabilitation: validity, reliability and responsiveness—a systematic review', *Physiotherapy,* 98(4), pp. 277-287. doi: 10.1016/j.physio.2011.11.003.

Bergström, H., *et al.* (2013) 'A multi-component universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: a cluster randomised controlled trial', *Research In Developmental Disabilities,* 34(11), pp. 3847-3857. doi: 10.1016/j.ridd.2013.07.019.

Bland, J. M. and Altman, D. G. (2010) 'Statistical methods for assessing agreement between two methods of clinical measurement', *International Journal of Nursing Studies,* 47(8), pp. 931-936. doi: 10.1016/j.ijnurstu.2009.10.001.

Bodde, A. E. and Seo, D. C. (2009) 'A review of social and environmental barriers to physical activity for adults with intellectual disabilities', *Disabil Health J,* 2(2), pp. 57-66. doi: 10.1016/j.dhjo.2008.11.004.

Bohannon, R. W. (2007) 'Number of pedometer- assessed steps taken per day by adults: a descriptive meta-analysis', *Physical therapy,* 87(12), pp. 1642.
Bouchard, C., Shephard, R. J. and Brubaker, P. H. (1994) 'Physical Activity, Fitness, and Health: Consensus Statement', *Medicine & Science in Sports & Exercise,* 26(1), pp. 119. doi: 10.1249/00005768-199401000-00024.
Bouchard, C., Shephard, R. J. and Stephens, T. (1993). Physical activity, fitness, and health: Consensus statement. Champaign, IL: Human Kinetics.
Boundless (2016) *The Four Social Revolutions*. Available at: https://www.boundless.com/sociology/textbooks/boundless-sociology-textbook/social-change-21/sources-of-social-change-139/the-four-social-revolutions-761-3396/ (Accessed: 13 July 2017).
Browne, R. H. (1995) 'On the use of a pilot sample for sample size determination', *Statistics in Medicine,* 14(17), pp. 1933-1940. doi: 10.1002/sim.4780141709.
Butler, E. and Evenson, K. (2014) 'Prevalence of Physical Activity and Sedentary Behavior Among Stroke Survivors in the United States', *Topics in Stroke Rehabilitation,* 21(3), pp. 246-255. doi: 10.1310/tsr2103-246.
Butte, N. F., Ekelund, U. and Westerterp, K. R. (2012) 'Assessing physical activity using wearable monitors: measures of physical activity', *Med Sci Sports Exerc,* 44(1 Suppl 1), pp. S5-12. doi: 10.1249/MSS.0b013e3182399c0e.
Cantor, A. B. (1996) 'Sample-size calculations for Cohen's kappa', *Psychological Methods,* 1(2), pp. 150-153. doi: 10.1037/1082-989X.1.2.150.
Cartwright, L.*, et al.* (2017) 'Barriers to increasing the physical activity of people with intellectual disabilities', *British Journal of Learning Disabilities,* 45(1), pp. 47-55. doi: 10.1111/bld.12175.
Caspersen, C. J., Powell, K. E. and Christenson, G. M. (1985) 'Physical Activity, Exercise,and Physical Fitness:Definitions and Distinctionsfor Health-Related Research', *Public Health Rep. ,* Vol. 100, No. 2 127, pp. 126–131.
Casperson, C. (1989) 'Physical activity epidemiology: Concepts, methods and applications to exercise science', in Pandolf, K. (ed.) *Exercise and sports science reviews*. Baltimore: Williams and Wilkins, pp. 423-473.
Celis-Morales, C. A.*, et al.* (2012) 'Objective vs. Self- Reported Physical Activity and Sedentary Time: Effects of Measurement Method on Relationships with Risk Biomarkers (Objective vs. Self- Reported Physical Activity)', *PLoS ONE,* 7(5), pp. e36345. doi: 10.1371/journal.pone.0036345.
Centers for Disease Control and Prevention, services (1999) *Historical background and evolution of physical activity recommendations*.
Chapman, J.*, et al.* (2015) 'The feasibility and acceptability of questionnaires and accelerometry for measuring physical activity and sedentary behaviour in adults with mental illness', *Journal of Mental Health,* 24(5), pp. 299. doi: 10.3109/09638237.2015.1057321.
Chau, J. Y.*, et al.* (2013) 'Daily Sitting Time and All- Cause Mortality: A Meta-Analysis', *PLoS ONE,* 8(11). doi: 10.1371/journal.pone.0080000.
Chen, Y. K. and Bassett, R. D. (2005) 'The Technology of Accelerometry-Based Activity Monitors: Current and Future', *Medicine & Science in Sports & Exercise,* 37(11 Suppl), pp. S490-S500. doi: 10.1249/01.mss.0000185571.49104.82.
Chief Medical Officer (2011) *Start Active, Stay Active: A report on physical activity for health from the four home countries*: Department of Health.
Clays, E.*, et al.* (2013) 'The association between leisure time physical activity and coronary heart disease among men with different physical work demands: a prospective cohort study', *Affiliated to the European Epidemiology Federation,* 28(3), pp. 241-247. doi: 10.1007/s10654-013-9764-4.
Cohen, J. (1960) 'A coefficient of agreement for nominal scales', *Educational and Psychological Measurement,* 20 pp. 37–46.

Cohen, J. (1988) *Statistical power analysis for the behavioral sciences.* 2nd edn. Hillsdale, N.J. ; London: L. Erlbaum Associates.
Craig, C. L.*, et al.* (2003) 'International Physical Activity Questionnaire: 12-Country Reliability and Validity', *Medicine & Science in Sports & Exercise,* 35(8), pp. 1381-1395.
Dairo, Y. M., Collett, J. and Dawes, H. (2017a) 'A feasibility study into the measurement of physical activity levels of adults with intellectual disabilities using accelerometers and the International Physical Activity Questionnaire', *British Journal of Learning Disabilities,* 45(2), pp. 129-137. doi: 10.1111/bld.12188.
Dairo, Y. M., Collett, J. and Dawes, H. (2017b) 'Optimising Participation in Physical Activity Research for Adults with Intellectual Disabilities', *World Academy of Science, Engineering and Technology, International Journal of Sport and Exercise Sciences,* 4(5). doi: http://waset.org/abstracts/59083.
Dairo, Y. M.*, et al.* (2016) 'Physical activity levels in adults with intellectual disabilities: A systematic review', *Preventive Medicine Reports,* 4, pp. 209-219. doi: http://dx.doi.org/10.1016/j.pmedr.2016.06.008.
de Bildt, A.*, et al.* (2005) 'The Psychometric Properties of the Vineland Adaptive Behavior Scales in Children and Adolescents with Mental Retardation', *Journal of Autism and Developmental Disorders,* 35(1), pp. 53-62. doi: 10.1007/s10803-004-1033-7.
de Rezende, L. F. M.*, et al.* (2014) 'Sedentary Behavior and Health Outcomes: An Overview of Systematic Reviews', *PLoS ONE,* 9(8). doi: 10.1371/journal.pone.0105620.
Deci, E. L. and Ryan, R. M. (2008) 'Self- Determination Theory: A Macrotheory of Human Motivation, Development, and Health', *Canadian Psychology/Psychologie canadienne,* 49(3), pp. 182-185. doi: 10.1037/a0012801.
Department of Culture Media and Sport (2002) *Game Plan: A strategy for delivering the governments sport and physical activity objectives.*
Department of Health, Health (2004) *At least 5 a week: physical activity and health outcomes: a review of the Chief Medical Officer.* London.
Ding, D.*, et al.* (2016) 'The economic burden of physical inactivity: a global analysis of major non-communicable diseases', *The Lancet,* 388(10051), pp. 1311-1324. doi: 10.1016/S0140-6736(16)30383-X.
Dixon-Ibarra, A., Lee, M. and Dugala, A. (2013) 'Physical Activity and Sedentary Behavior in Older Adults With Intellectual Disabilities: A Comparative Study', *Adapted Physical Activity Quarterly,* 30(1), pp. 1-19.
Dodd, K. J. and Shield, N. (2005) 'A systematic review of the outcomes of cardiovascular exercise programs for people with Down syndrome.', *Archives of Physical Medicine and Rehabilitation,* 86, pp. 2051-2058.
Doran, C. M.*, et al.* (2012) 'How much does intellectual disability really cost? First estimates for Australia', *Journal of Intellectual & Developmental Disability,* 37(1), pp. 42-49. doi: 10.3109/13668250.2011.648609.
Downs, S. H. and Black, N. (1998) 'The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions', *Journal of Epidemiology and Community Health,* 52(6), pp. 377. doi: 10.1136/jech.52.6.377.
Draheim, C. C., Williams, D. P. and McCubbin, J. A. (2002) 'Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation', *Mental Retardation,* 40(6), pp. 436-444.
Dubois, M.-F.*, et al.* (2011) 'Comfort with proxy consent to research involving decisionally impaired older adults: do type of proxy and risk-benefit profile matter?', *International Psychogeriatrics,* 23(9), pp. 1479-1488. doi: 10.1017/S1041610211000433.

Einarsson, I. Þ., *et al.* (2016) 'Physical activity during school and after school among youth with and without intellectual disability', *Research in Developmental Disabilities,* 56, pp. 60-70. doi: 10.1016/j.ridd.2016.05.016.
Ekelund, U. (2012) 'Commentary: Too much sitting—a public health threat?', *International Journal of Epidemiology,* 41(5), pp. 1353-1355. doi: 10.1093/ije/dys128.
Ekelund, U., Aman, J. and Westerterp, K. (2003) 'Is the ArteACC index a valid indicator of free-living physical activity in adolescents?', *Obesity research,* 11(6), pp. 793.
Ekelund, U., *et al.* (2006) 'Criterion- related validity of the last 7- day, short form of the International Physical Activity Questionnaire in Swedish adults', *Public health nutrition,* 9(2), pp. 258.
Ekelund, U., *et al.* (2001) 'Physical activity assessed by activity monitor and doubly labeled water in children', *Medicine and science in sports and exercise,* 33(2), pp. 275.
Emerson, E. (2005) 'Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England', *Journal of Intellectual Disability Research,* 49(Part 2), pp. 134-143.
Emerson, E. and Baines, S. (2011) 'Health inequalities and people with learning disabilities in the UK', *Tizard Learning Disability Review,* 16(1), pp. 42.
Emerson, E., *et al.* (2014) 'Trends in age-standardised mortality rates and life expectancy of people with learning disabilities in Sheffield over a 33-year period', *Tizard Learning Disability Review,* 19(2), pp. 90-95. doi: http://dx.doi.org/10.1108/TLDR-01-2014-0003.
Emerson, E., *et al.* (2001) *Learning disabilities : the fundamental facts.* London: Foundation for People with Learning Disabilities.
Emerson, E. and Parish, S. (2010) 'Intellectual disability and poverty: Introduction to the special section', *Journal of Intellectual and Developmental Disability, 2010, Vol.35(4), p.221-223,* 35(4), pp. 221-223. doi: 10.3109/13668250.2010.525869.
English, C., *et al.* (2014) 'Physical Activity and Sedentary Behaviors in People With Stroke Living in the Community: A Systematic Review', *Physical Therapy,* 94(2), pp. 185-196. doi: 10.2522/ptj.20130175.
Esliger, D. W., *et al.* (2011) 'Validation of the GENEA Accelerometer', *Medicine and science in sports and exercise,* 43(6), pp. 1085. doi: 10.1249/MSS.0b013e31820513be.
Finlay, W. M. L. and Lyons, E. (2001) 'Methodological Issues in Interviewing and Using Self- Report Questionnaires With People With Mental Retardation', *Psychological Assessment,* 13(3), pp. 319-335. doi: 10.1037/1040-3590.13.3.319.
Finlayson, J., *et al.* (2009) 'Understanding Predictors of Low Physical Activity in Adults with Intellectual Disabilities', *Journal of Applied Research in Intellectual Disabilities,* 22(3), pp. 236-247. doi: 10.1111/j.1468-3148.2008.00433.x.
Finlayson, J., Turner, A. and Granat, M. H. (2011) 'Measuring the Actual Levels and Patterns of Physical Activity/Inactivity of Adults with Intellectual Disabilities', *Journal of Applied Research in Intellectual Disabilities,* (6), pp. 508-517. doi: 10.1111/j.1468-3148.2011.00633.x.
Fishbein, M., *et al.* (2001) 'Factors influencing behaviour and behaviour change.', in Baum A, R.T., Singer J. (ed.) *Handbook of HealthPsychology.* Mahwah, New Jersey: Lawrence Erlbaum Associates pp. 3-17.
Fisher, K. J. (2014) 'Purpose-based or knowledge-based intention for collective wrongdoing in international criminal law?', 10(2), pp. 163-176. doi: 10.1017/S1744552314000020.
Fitzgerald, J. D., *et al.* (2015) 'Association of objectively measured physical activity with cardiovascular risk in mobility-limited older adults', *J Am Heart Assoc,* 4(2). doi: 10.1161/jaha.114.001288.

Ford, E. S. and Caspersen, C. J. (2012) 'Sedentary behaviour and cardiovascular disease: a review of prospective studies', *International Journal of Epidemiology,* 41(5), pp. 1338-1353. doi: 10.1093/ije/dys078.
Foundation for People with Learning Disabilities, F. (2012) *About us* Online. Available at: http://www.learningdisabilities.org.uk/about-us/ (Accessed: 19 March).
Francis, J. J.*, et al.* (2004). Constructing questionnaires based on the theory of planned behaviour. A manual for health services researchers. University of Newcastle upon Tyne: Centre for Health Services Research.
Freedson, P. and Miller, K. (2000) 'Objective monitoring of physical activity using motion sensors and heart rate', *Research Quarterly For Exercise and Sport,* 71(2), pp. S21-S29.
Freedson, P. S., Melanson, E. and Sirard, J. (1998) 'Calibration of the Computer Science and Applications, Inc. accelerometer', *Medicine and science in sports and exercise,* 30(5), pp. 777.
Frey, G. C. (2004) 'Comparison of Physical Activity Levels Between Adults With and Without Mental Retardation', *Journal of Physical Activity & Health,* 1(3), pp. 235-245.
Gates, B. and Atherton, H. (2007). Learning disabilities : towards inclusion. 5th ed. Edinburgh; New York: Elsevier.
Gill, D. P.*, et al.* (2012) 'Using a single question to assess physical activity in older adults: a reliability and validity study', *BMC Medical Research Methodology,* 12, pp. 20-20. doi: 10.1186/1471-2288-12-20.
Gorman, E.*, et al.* (2014) 'Accelerometry analysis of physical activity and sedentary behavior in older adults: a systematic review and data analysis', *Eur Rev Aging Phys Act,* 11(1), pp. 35-49. doi: 10.1007/s11556-013-0132-x.
Green, S. B. (1991) 'How Many Subjects Does It Take To Do A Regression Analysis', *Multivariate Behav Res,* 26(3), pp. 499-510. doi: 10.1207/s15327906mbr2603_7.
Hale, L. A., Pal, J. and Becker, I. (2008) 'Measuring free-living physical activity in adults with and without neurologic dysfunction with a triaxial accelerometer', *Arch Phys Med Rehabil,* 89(9), pp. 1765-71. doi: 10.1016/j.apmr.2008.02.027.
Hall, K, H. and Kerr, A. W. (2001) 'Goal setting in sport and physical activity: Tracing empirical developments and establishing conceptual direction', in Roberts, G.C. (ed.) *Motivation in Sport and Exercise* 2nd edn.: Human Kinetics Publishers, pp. 183-234.
Hallal, P. C.*, et al.* (2012) 'Global physical activity levels: surveillance progress, pitfalls, and prospects', *The Lancet,* 380(9838), pp. 247-257. doi: 10.1016/S0140-6736(12)60646-1.
Harris, J. C. (2006) *Understanding its development, causes, classification, evaluation, and treatment.* New York: Oxford University Press
Harrison, P. L. and Oakland, T. (2003) *Adaptive Behaviour Assessment System.* 2nd edn. San Antonio: The Psychological Corporation.
Hartling, L.*, et al.* (2013) 'Testing the Newcastle Ottawa Scale showed low reliability between individual reviewers', *Journal of Clinical Epidemiology,* 66(9), pp. 982-993. doi: 10.1016/j.jclinepi.2013.03.003.
Haveman, M.*, et al.* (2011) 'Ageing and health status in adults with intellectual disabilities: Results of the European POMONA II study', *Journal of Intellectual & Developmental Disability,* 36(1), pp. 49-60. doi: 10.3109/13668250.2010.549464.
Hawkins, A. and Look, R. (2006) 'Levels of engagement and barriers to physical activity in a population of adults with learning disabilities', *British Journal of Learning Disabilities,* 34(4), pp. 220-226.
Heady, J. A.*, et al.* (1961) 'Coronary heart disease in London busmen. A progress report with particular reference to physique', *British journal of preventive & social medicine,* 15, pp. 143.

Health and Social Care Information Centre (2011) *Social Care and Mental Health Indicators from the National Indicator Set*. Available at: https://data.gov.uk/dataset/social-care-and-mental-health-indicators-from-the-national-indicator-set.
Heller, T., Hsieh, K. and Rimmer, J. (2002) 'Barriers and supports for exercise participation among adults with Down syndrome', *Journal of Gerontological Social Work,* 38(1/2), pp. 161-178.
Heslop, P.*, et al.* (2014) 'The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study', *The Lancet,* 383(9920), pp. 889-95.
Hilgenkamp, T. I. M.*, et al.* (2012) 'Physical activity levels in older adults with intellectual disabilities are extremely low', *Research In Developmental Disabilities,* 33(2), pp. 477-483. doi: 10.1016/j.ridd.2011.10.011.
Hinckson, E. A.*, et al.* (2013) 'Physical activity, dietary habits and overall health in overweight and obese children and youth with intellectual disability or autism', *Research In Developmental Disabilities,* 34(4), pp. 1170-1178. doi: 10.1016/j.ridd.2012.12.006.
Hinkin, T. R., Tracey, J. B. and Enz, C. A. (1997) 'Scale Construction: Developing Reliable and Valid Measurement Instruments', *Journal of Hospitality & Tourism Research,* 21(1), pp. 100-120. doi: 10.1177/109634809702100108.
Holland, A. (2000) 'Ageing and learning disability', *British Journal Of Psychiatry,* 176, pp. 26-31.
Honeycutt, A.*, et al.* (2004). Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment--United States, 2003.
Hsieh, K., Rimmer, J. H. and Heller, T. (2014) 'Obesity and associated factors in adults with intellectual disability', *Journal of Intellectual Disability Research,* 58(9), pp. 851-863. doi: 10.1111/jir.12100.
Hutzler, Y. and Korsensky, O. (2010) 'Motivational Correlates of Physical Activity in Persons with an Intellectual Disability: A Systematic Literature Review', *Journal of Intellectual Disability Research,* 54(9), pp. 767-786. doi: 10.1111/j.1365-2788.2010.01313.x.
Ingram, D. K. (2000) 'Age-related decline in physical activity: generalization to nonhumans', *Med Sci Sports Exerc,* 32(9), pp. 1623-9.
International Physical Activity Questionnaire (2002) *Short last 7 days self-administered format*. Available at: https://sites.google.com/site/theipaq/questionnaire_links (Accessed: 15th August).
Jackson, A.*, et al.* (2007) 'Construct Validity Evidence for Single- Response Items to Estimate Physical Activity Levels in Large Sample Studies', *Research Quarterly for Exercise and Sport,* 78(2), pp. 24-31. doi: 10.1080/02701367.2007.10599400.
Jancey, J.*, et al.* (2006) 'Effective Recruitment and Retention of Older Adults in Physical Activity Research: PALS Study', *American Journal of Health Behavior,* 30(6), pp. 626-35.
Janney, C.*, et al.* (2014) 'Are adults with bipolar disorder active? Objectively measured physical activity and sedentary behavior using accelerometry', *Journal of Affective Disorders,* 152, pp. 498-504. doi: http://dx.doi.org/10.1016/j.jad.2013.09.009.
Jenkins, C. M. and McKenzie, K. (2011) 'The Application of the Theory of Planned Behaviour to Diet in Carers of People with an Intellectual Disability', *Journal of Applied Research in Intellectual Disabilities,* 24(3), pp. 237-246. doi: 10.1111/j.1468-3148.2010.00594.x.
Julious, S. A. (2005) 'Sample size of 12 per group rule of thumb for a pilot study', *Pharmaceutical Statistics,* 4(4), pp. 287-291. doi: 10.1002/pst.185.
Kantor, J. R. (1923) 'An Objective Analysis of Volitional Behavior', *Psychological Review,* 30(2), pp. 116-144. doi: 10.1037/h0075494.

Katz, G. and Lazcano-ponce, E. (2008) 'Intellectual disability: definition, etiological factors, classification, diagnosis, treatment and prognosis', *Salud Pública de México,* 50 Suppl 2, pp. 132-41. doi: 10.1590/S0036-36342008000800005.
Katzmarzyk, P. T. and Lee, I. M. (2012) 'Sedentary behaviour and life expectancy in the USA: a cause-deleted life table analysis', *BMJ Open,* 2(4).
Knottnerus, A. and Tugwell, P. (2008) 'STROBE—A checklist to STrengthen the Reporting of OBservational studies in Epidemiology', *Journal of Clinical Epidemiology* 61(4), pp. 323-323. doi: 10.1016/j.jclinepi.2007.11.006.
Kottner, J. (2009) 'Interrater reliability and the kappa statistic: A comment on Morris et al. (2008)', *International Journal of Nursing Studies,* 46(1), pp. 141-142. doi: 10.1016/j.ijnurstu.2008.04.001.
Kozey-Keadle, S.*, et al.* (2011) 'Validation of wearable monitors for assessing sedentary behavior', *Medicine and science in sports and exercise,* 43(8), pp. 1561. doi: 10.1249/MSS.0b013e31820ce174.
Kraemer, H. C. and Jacklin, C. N. (1979) 'Statistical Analysis of Dyadic Social Behavior', *Psychological Bulletin,* 86(2), pp. 217-24.
Krahn, G. L., Hammond, L. and Turner, A. (2006) 'A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities', *Mental Retardation and Developmental Disabilities Research Reviews,* 12(1), pp. 70-82. doi: 10.1002/mrdd.20098.
Kruisdijk, F.*, et al.* (2017) 'Accelerometer-measured sedentary behaviour and physical activity of inpatients with severe mental illness ', *Psychiatry Research,* 254, pp. 67-74. doi: http://dx.doi.org/10.1016/j.psychres.2017.04.035.
Kyu, H. H.*, et al.* (2016) 'Physical activity and risk of breast cancer, colon cancer, diabetes, ischemic heart disease, and ischemic stroke events: systematic review and dose- response meta- analysis for the Global Burden of Disease Study 2013', *BMJ,* 354. doi: 10.1136/bmj.i3857.
LaMorte, W. W. (2016) *Central Limit Theorem*. Online: Boston University School of Public Health. Available at: http://sphweb.bumc.bu.edu/otlt/mph-modules/bs/bs704_probability/BS704_Probability12.html (Accessed: 20th April).
Lancaster, G. A., Dodd, S. and Williamson, P. R. (2004) 'Design and analysis of pilot studies: recommendations for good practice', *Journal of evaluation in clinical practice,* 10(2), pp. 307.
Langan, S. M.*, et al.* (2011) 'STROBE and reporting observational studies in dermatology', *The British journal of dermatology,* 164(1), pp. 1. doi: 10.1111/j.1365-2133.2010.10136.x.
Lante, K., Reece, J. and Walkley, J. (2010) 'Energy expended by adults with and without intellectual disabilities during activities of daily living', *Research In Developmental Disabilities,* 31(6), pp. 1380-1389. doi: 10.1016/j.ridd.2010.06.022.
Lee, P.*, et al.* (2011). Validity of the international physical activity questionnaire short form (IPAQ- SF): A systematic review. *Int. J. Behav. Nutr. Phys. Act.*
Leenders, N. Y.*, et al.* (2001) 'Evaluation of methods to assess physical activity in free-living conditions', *Medicine and science in sports and exercise,* 33(7), pp. 1233.
Li, S., Carlson, E. and Holm, K. (2000) 'Validation of a single-item measure of usual physical activity', *Percept Mot Skills,* 91(2), pp. 593-602. doi: 10.2466/pms.2000.91.2.593.
Lifestyles statistics team (2014) 'Statistics on Obesity, Physical Activity and Diet: England'. http://www.hscic.gov.uk/catalogue/PUB13648/Obes-phys-acti-diet-eng-2014-rep.pdf.
Likert, R. (1932) 'A technique for the measurement of attitudes.', *Archives of Psychology* 140, pp. 1-55.
Lin, P.-Y., Lin, L.-P. and Lin, J.-D. (2010) 'Hypertension, Hyperglycemia, and Hyperlipemia among Adolescents with Intellectual Disabilities', *Research in*

Developmental Disabilities: A Multidisciplinary Journal, 31(2), pp. 545-550. doi: 10.1016/j.ridd.2009.12.002.
Litwin, M. S. (1995) *How to measure survey reliability and validity.* Thousand Oaks ; London: Thousand Oaks ; London : Sage.
Livingstone, S. (1996) 'On the continuing problem of media effects research', in Gurevitch, J.C.a.M. (ed.) *Mass media and society.* 2nd Edition edn. London, UK: Edward Arnold pp. 305 – 324.
MacDonnell, A. (2014) 'Learning disabilities'. Online: Buckinghamshire County Council. Available at: https://www.buckscc.gov.uk/media/1197755/Learning-disabilities.pdf (Accessed: 28 July 2016).
Macnamara, Á. and Collins, D. (2011) 'Development and initial validation of the Psychological Characteristics of Developing Excellence Questionnaire', *Journal of Sports Sciences,* 29(12), pp. 1273-1286. doi: 10.1080/02640414.2011.589468.
Maddison, R.*, et al.* (2007) 'International Physical Activity Questionnaire (IPAQ) and New Zealand Physical Activity Questionnaire (NZPAQ): a doubly labelled water validation', *The international journal of behavioral nutrition and physical activity,* 4, pp. 62.
Magaziner, J.*, et al.* (1996) 'Use of proxies to measure health and functional status in epidemiologic studies of community-dwelling women aged 65 years and older', *American journal of epidemiology,* 143(3), pp. 283.
Magaziner, J.*, et al.* (1997) 'Proxy Reporting in Five Areas of Functional Status', *American journal of epidemiology,* 146(5), pp. 418-428.
Malina, R. M. (2004). Growth, maturation, and physical activity. *In:* Bouchard, C. & Bar-Or, O. (eds.) 2nd ed. ed. Champaign, Ill. ; Leeds: Champaign, Ill. ; Leeds : Human Kinetics.
Martin, E.*, et al.* (2011) 'Care staff intentions to support adults with an intellectual disability to engage in physical activity: an application of the Theory of Planned Behaviour', *Research In Developmental Disabilities,* 32(6), pp. 2535-2541. doi: 10.1016/j.ridd.2011.07.006.
Mathie, M. J.*, et al.* (2004) 'Accelerometry: providing an integrated, practical method for long-term, ambulatory monitoring of human movement', *Physiol Meas,* 25(2), pp. R1-20.
Matthews, L.*, et al.* (2011) 'Agreement of accelerometer and a physical activity questionnaire in adults with intellectual disabilities', *Preventive Medicine,* 52(5), pp. 361-364. doi: http://dx.doi.org/10.1016/j.ypmed.2011.02.001.
Maulik, P. K. and Harbour, C. K. (2010) 'Epidemiology of Intellectual Disability. In J. H. Stone & M. Blouin (Eds.) ', in International Encyclopedia of Rehabilitation. Buffalo & Exchange., C.f.I.R.R.I.a. (eds.).
Maulik, P. K.*, et al.* (2011) 'Prevalence of intellectual disability: a meta-analysis of population-based studies', *Res Dev Disabil,* 32(2), pp. 419-36. doi: 10.1016/j.ridd.2010.12.018.
McDonald, J. H. (2014a) 'One-way anova', *Handbook of Biological Statistics* 3rd edn. Baltimore, Maryland. : Sparky House Publishing, pp. pages 145-156.
McDonald, J. H. (2014b) 'Small numbers in chi-square and *G*–tests', *Handbook of Biological Statistics* 3rd ed. edn. Maryland, USA.: Sparky House Publishing, Baltimore, Maryland., pp. pages 86-89
McDonald, K. E. and Keys, C. B. (2008) 'How the Powerful Decide: Access to Research Participation by those at the Margins', *American Journal of Community Psychology,* 42(1-2), pp. 79-93. doi: 10.1007/s10464-008-9192-x.
McEachan, R. R. C.*, et al.* (2011) 'Prospective prediction of health- related behaviours with the Theory of Planned Behaviour: a meta- analysis', *Health Psychology Review,* 5(2), pp. 97-144. doi: 10.1080/17437199.2010.521684.

McGarty, A. M., Penpraze, V. and Melville, C. A. (2015) 'Feasibility of a laboratory-based accelerometer calibration protocol for children with intellectual disabilities', *Pilot and Feasibility Studies,* 1. doi: 10.1186/s40814-015-0014-2.
McGuire, B. E., Daly, P. and Smyth, F. (2007) 'Lifestyle and health behaviours of adults with an intellectual disability', *Journal of Intellectual Disability Research,* 51(7), pp. 497-510. doi: 10.1111/j.1365-2788.2006.00915.x.
McKeon, M., Slevin, E. and Taggart, L. (2013) 'A pilot survey of physical activity in men with an intellectual disability', *Journal of Intellectual Disabilities,* 17(2), pp. 157-167. doi: 10.1177/1744629513484666.
Melville, C. A.*, et al.* (2017) 'Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities — A systematic review', *Preventive Medicine,* 97, pp. 62-71. doi: 10.1016/j.ypmed.2016.12.052.
Messent, P. R., Cooke, C. B. and Long, J. (1999) 'Primary and secondary barriers to physically active healthy lifestyles for adults with learning disabilities', *Disability & Rehabilitation,* 21(9), pp. 409-419.
Michie, S., van Stralen, M. M. and West, R. (2011) 'The behaviour change wheel: A new method for characterising and designing behaviour change interventions', *Implementation Science,* 6(1), pp. 42. doi: 10.1186/1748-5908-6-42.
Milton, K., Bull, F. C. and Bauman, A. (2011) 'Reliability and validity testing of a single-item physical activity measure', *British Journal of Sports Medicine,* 45(3), pp. 203. doi: 10.1136/bjsm.2009.068395.
Milton, K., Clemes, S. and Bull, F. (2013) 'Can a single question provide an accurate measure of physical activity?', *British Journal of Sports Medicine,* 47(1), pp. 44. doi: 10.1136/bjsports-2011-090899.
Moher, D.*, et al.* (2009) 'Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement', *Annals of internal medicine,* 151(4), pp. 264.
Mokkink, L. B.*, et al.* (2010) 'The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study', *Quality of Life Research,* 19(4), pp. 539-549. doi: 10.1007/s11136-010-9606-8.
Morris, J. N. and Crawford, M. D. (1958) 'Coronary heart disease and physical activity of work', *British Medical Journal,* 2(5111).
Morris, J. N.*, et al.* (1953) 'Coronary heart disease and physical activity of work', *The Lancet,* 265, pp. 1111-1120.
Moss, S. J. and Czyz, S. H. (2016) 'Level of agreement between physical activity levels measured by ActiHeart and the International Physical Activity Questionnaire in persons with intellectual disability', *Disability and Rehabilitation*, pp. 1-7. doi: 10.1080/09638288.2016.1258092.
Murphy, M.*, et al.* (2007) 'The effect of walking on fitness, fatness and resting blood pressure: A meta-analysis of randomised, controlled trials', *Preventive Medicine,* 44(5), pp. 377-385. doi: 10.1016/j.ypmed.2006.12.008.
Murtagh, E.*, et al.* (2015) 'The effect of walking on risk factors for cardiovascular disease: An updated systematic review and meta-analysis of randomised control trials', *Preventive Medicine,* 72, pp. 34-43. doi: 10.1016/j.ypmed.2014.12.041.
Nardi, P. M. (2006) *Doing survey research : a guide to quantitative methods.* 2nd ed. edn. Boston: Boston : Pearson/Allyn & Bacon.
Neyman, J. (1934) 'On the Two Different Aspects of the Representative Method: The Method of Stratified Sampling and the Method of Purposive Selection', *Journal of the Royal Statistical Society,* 97(4), pp. 558-625. doi: 10.2307/2342192.
NHS Choices (2015) *Assessing capacity to give consent:* . Available at: http://www.nhs.uk/CONDITIONS/CONSENT-TO-TREATMENT/Pages/Capacity.aspx Assessed 07/12/2015.
NIHR (2017) *Feasibility and pilot studies*. NIHR NETSCC glossary. Online. Available at: www.netscc.ac.uk/glossary/#glos6 (Accessed: 10th October).
Nola, R. (2007) *Theories of scientific method : an introduction.* Chesham: Acumen.

Norman, P., Conner, M. and Bell, R. (1999) 'The Theory of Planned Behavior and Smoking Cessation', *Health Psychology,* 18(1), pp. 89-94. doi: 10.1037/0278-6133.18.1.89.
Ohkawara, K.*, et al.* (2011) 'Real-time estimation of daily physical activity intensity by a triaxial accelerometer and a gravity-removal classification algorithm', *Br J Nutr,* 105(11), pp. 1681-1691. doi: 10.1017/S0007114510005441.
Ohwada, H.*, et al.* (2005) 'Energy expenditure in males with mental retardation', *Journal Of Nutritional Science And Vitaminology,* 51(2), pp. 68-74.
Owen, J.*, et al.* (2014) 'Representativeness of two sampling procedures for an internet intervention targeting cancer-related distress: a comparison of convenience and registry samples', *Journal of Behavioral Medicine,* 37(4), pp. 630-641. doi: 10.1007/s10865-013-9509-6.
Owen, N.*, et al.* (2010) 'Too Much Sitting: The Population-Health Science of Sedentary Behavior', *Exercise and Sport Sciences Reviews,* 38(3), pp. 105-113. doi: 10.1097/JES.0b013e3181e373a2.
Owlia, G.*, et al.* (1995) 'Influence of Reinforcers on the Time-on-Task Performance of Adolescents Who Are Profoundly Mentally Retarded', *Adapted Physical Activity Quarterly,* 12(3), pp. 275-288. doi: 10.1123/apaq.12.3.275.
Peterson, J. J., Janz, K. F. and Lowe, J. B. (2008) 'Physical activity among adults with intellectual disabilities living in community settings', *Preventive Medicine,* 47(1), pp. 101-106.
Phillips, A. C. and Holland, A. J. (2011) 'Assessment of objectively measured physical activity levels in individuals with intellectual disabilities with and without Down's syndrome', *Plos One,* 6(12), pp. e28618-e28618. doi: 10.1371/journal.pone.0028618.
Pratt, H. D. and Greydanus, D. E. (2007) 'Intellectual Disability (Mental Retardation) in Children and Adolescents', *Primary Care: Clinics in Office Practice,* 34(2), pp. 375-386. doi: 10.1016/j.pop.2007.04.010.
Prince, S.*, et al.* (2008) 'A comparison of direct versus self-report measures for assessing physical activity in adults: a systematic review', *International Journal of Behavioral Nutrition and Physical Activity,* 5. doi: 10.1186/1479-5868-5-56.
Public Health England (2016) *Physical Activity*. Online: Public Health England. Available at: http://fingertips.phe.org.uk/profile/physical-activity (Accessed: January 22nd).
Public Health England (2017) *Health Profiles* 1-4. Online: Public Health England. Available at: http://fingertipsreports.phe.org.uk/health-profiles/2017/e10000025.pdf (Accessed: 11th July).
Reissmann, D.*, et al.* (2013) 'Insufficient diagnostic accuracy of a single- item questionnaire to detect psychosocial distress in temporomandibular disorder patients', *Clinical Oral Investigations,* 17(8), pp. 1937-45. doi: 10.1007/s00784-012-0892-0.
Richards, J.*, et al.* (2013) 'Face-to-face interventions for promoting physical activity', *Cochrane Database of Systematic Reviews,* 9.
Robertson, J.*, et al.* (2000) 'Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities', *Research In Developmental Disabilities,* 21(6), pp. 469-486.
Saaltink, R.*, et al.* (2012) 'Protection, Participation and Protection through Participation: Young People with Intellectual Disabilities and Decision Making in the Family Context', *Journal of Intellectual Disability Research,* 56(11), pp. 1076-1086. doi: 10.1111/j.1365-2788.2012.01649.x.
Sallis, J. and Saelens, B. (2000) 'Assessment of physical activity by self-report: Status, limitations, and future directions', *Research Quarterly For Exercise and Sport,* 71(2), pp. S1-S14.
Sallis, J. F., Bauman, A. and Pratt, M. (1998) 'Environmental and policy interventions to promote physical activity', *Am J Prev Med,* 15(4), pp. 379-97.

Salvador-Carulla, L.*, et al.* (2011) 'Intellectual developmental disorders: towards a new name, definition and framework for "mental retardation/ intellectual disability" in ICD-11', *World psychiatry : official journal of the World Psychiatric Association (WPA),* 10(3), pp. 175.

Schifter, D. E. and Ajzen, I. (1985) 'Intention, perceived control, and weight loss: An application of the theory of planned behavior', *Journal of Personality and Social Psychology,* 49(3), pp. 843-851. doi: 10.1037/0022-3514.49.3.843.

Sedentary Behaviour Research Network (2012) 'Letter to the editor: standardized use of the terms " sedentary" and " sedentary behaviours&#034', *Applied physiology, nutrition, and metabolism = Physiologie appliquee, nutrition et metabolisme,* 37(3), pp. 540. doi: 10.1139/h2012-024.

Sefa, L. and Neslihan, L. (2015). An Analysis of the Effects of the Physical Activities On the Cognitive Functions of the Old People with Mild Cognitive Impairment.

Shephard, R. and Vuillemin, A. (2003) 'Limits to the measurement of habitual physical activity by questionnaires', *British Journal of Sports Medicine,* 37(3), pp. 197-206. doi: 10.1136/bjsm.37.3.197.

Shields, N.*, et al.* (2014) 'Is participation among children with intellectual disabilities in outside school activities similar to their typically developing peers? A systematic review', *Developmental Neurorehabilitation,* 17(1), pp. 64-71. doi: 10.3109/17518423.2013.836256.

Shrout, P. (1998) 'Measurement reliability and agreement in psychiatry', *Statistical Methods in Medical Research,* 7(3), pp. 301-17. doi: 10.1191/096228098672090967.

Silsbury, Z., Goldsmith, R. and Rushton, A. (2015) 'Systematic review of the measurement properties of self- report physical activity questionnaires in healthy adult populations', *BMJ open,* 5(9), pp. e008430. doi: 10.1136/bmjopen-2015-008430.

Sjoholm, A.*, et al.* (2014) 'Sedentary Behaviour and Physical Activity of People with Stroke in Rehabilitation Hospitals ', *Stroke Research and Treatment*. doi: http://dx.doi.org/10.1155/2014/591897.

Sport England (2016) *Record Number of Women Get Active*. Online: Active People Survey England (Accessed: 7th June 2017).

Stamatakis, E.*, et al.* (2012) 'Sedentary time in relation to cardio-metabolic risk factors: differential associations for self-report vs accelerometry in working age adults', *International Journal of Epidemiology,* 41(5), pp. 1328-1337. doi: 10.1093/ije/dys077.

Stancliffe, R. J. and Anderson, L. L. (2017) 'Factors associated with meeting physical activity guidelines by adults with intellectual and developmental disabilities', *Research in Developmental Disabilities,* 62, pp. 1-14. doi: 10.1016/j.ridd.2017.01.009.

Stanish, H. I. (2004) 'Accuracy of pedometers and walking activity in adults with mental retardation', *Adapted Physical Activity Quarterly,* 21(2), pp. 167-179.

Stanish, H. I. and Draheim, C. C. (2005a) 'Assessment of walking activity using a pedometer and survey in adults with mental retardation', *Adapted Physical Activity Quarterly,* 22(2), pp. 136-145.

Stanish, H. I. and Draheim, C. C. (2005b) 'Walking habits of adults with mental retardation', *Mental Retardation,* 43(6), pp. 421-427.

Stanish, H. I. and Frey, G. C. (2008) 'Promotion of physical activity in individuals with intellectual disability', *Salud pública de México,* 50, pp. s178.

Stojanowski, C. M. and Knudson, K. J. (2011) 'Biogeochemical inferences of mobility of early Holocene fisher-foragers from the Southern Sahara Desert', *American Journal of Physical Anthropology,* 146(1), pp. 49-61. doi: 10.1002/ajpa.21542.

Strath, S. J.*, et al.* (2013) 'Guide to the assessment of physical activity: clinical and research applications: a scientific statement from the American Heart

Association.(AHA Scientific Statement)(Report)', *Circulation,* 128(20), pp. 2259-2279.
Temple, V. A. (2007) 'Barriers, enjoyment, and preference for physical activity among adults with intellectual disability', *Int J Rehabil Res,* 30(4), pp. 281-7. doi: 10.1097/MRR.0b013e3282f144fb.
Temple, V. A., Frey, G. C. and Stanish, H. I. (2006) 'Physical activity of adults with mental retardation: review and research needs', *American Journal Of Health Promotion: AJHP,* 21(1), pp. 2-12.
Temple, V. A. and Walkley, J. W. (2007) 'Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability', *Journal of Intellectual & Developmental Disability,* 32(1), pp. 28-38.
The Office of Disease Prevention and Health Promotion (*2008*) *Physical Activity Guidelines for Americans Summary*. Available at: http://health.gov/paguidelines/guidelines/summary.aspx (Accessed: 21 September 2015).
Tomioka, K.*, et al.* (2011) 'Reliability and Validity of the International Physical Activity Questionnaire (IPAQ) in Elderly Adults: The Fujiwara-kyo Study', *Journal of Epidemiology,* 21(6), pp. 459-465. doi: 10.2188/jea.JE20110003.
Tudor-Locke, C.*, et al.* (2008) 'Revisiting "how many steps are enough?"', *Med Sci Sports Exerc,* 40(7 Suppl), pp. S537-43. doi: 10.1249/MSS.0b013e31817c7133.
Tudor-Locke, C.*, et al.* (2011) 'Accelerometer steps/day translation of moderate-to-vigorous activity', *Preventive Medicine,* 53(1), pp. 31-33. doi: 10.1016/j.ypmed.2011.01.014.
Tudor-Locke, C. and Myers, A. (2001) 'Challenges and opportunities for measuring physical activity in sedentary adults', *Sports Medicine,* 31(2), pp. 91-100. doi: 10.2165/00007256-200131020-00002.
Tuffrey-Wijne, I. and McEnhill, L. (2008) 'Communication difficulties and intellectual disability in end-of-life care', *Int J Palliat Nurs,* 14(4), pp. 189-94. doi: 10.12968/ijpn.2008.14.4.29133.
Tweedy, S. M. and Trost, S. G. (2005) 'Validity of accelerometry for measurement of activity in people with brain injury', *Med Sci Sports Exerc,* 37(9), pp. 1474-80.
Tyrer, F.*, et al.* (2008) 'The Leicestershire intellectual disability tool: A simple measure to identify moderate to profound intellectual disability', *J. Appl. Res. Intellect. Disabil.,* 21(3), pp. 268-276. doi: 10.1111/j.1468-3148.2007.00409.x.
UKactive (2014) *Turning the tide of inactivity*. Online: www.ukactive.com/turningthetide. Available at: http://ukactive.com/downloads/managed/Turning_the_tide_of_inactivity.pdf (Accessed: 10 March 2018).
Van Aerde, J. (2015) *The Behaviour Change Wheel:A Guide to Designing Interventions* Book review. Online: The Canadian Journal of Physician Leadership. Available at: http://www.physicianleaders.ca/assets/cspljournalsummer2015.pdf#page=26 (Accessed: 23rd January).
van der Ploeg, H. P.*, et al.* (2012) 'Sitting time and all-cause mortality risk in 222 497 australian adults', *Archives of Internal Medicine,* 172(6), pp. 494-500. doi: 10.1001/archinternmed.2011.2174.
van der Putten, A. A. J.*, et al.* (2016) 'Motor activation in people with profound intellectual and multiple disabilities in daily practice', *Journal of Intellectual and Developmental Disability*. doi: 10.3109/13668250.2016.1181259
Vancampfort, D.*, et al.* (2016) 'Physical activity and sedentary behavior in people with bipolar disorder: A systematic review and meta-analysis', *Journal of Affective Disorders,* 201, pp. 145-152. doi: 10.1016/j.jad.2016.05.020.
Vocabulary.com (2017) 'Vocabulary.com', *Definition of Intention.* Online: Copyright ©1998-2017 Thinkmap, Inc.
Walker, A. R. P., Walker, B. F. and Adam, F. (2003) 'Nutrition, diet, physical activity, smoking, and longevity: From primitive hunter- gatherer to present passive

consumer—How far can we go?', *Nutrition,* 19(2), pp. 169-173. doi: 10.1016/S0899-9007(02)00948-6.
Wallén, E. F.*, et al.* (2009) 'High prevalence of cardio-metabolic risk factors among adolescents with intellectual disability', *Acta Paediatrica (Oslo, Norway: 1992),* 98(5), pp. 853-859. doi: 10.1111/j.1651-2227.2008.01197.x.
Waninge, A.*, et al.* (2013) 'Heart rate and physical activity patterns in persons with profound intellectual and multiple disabilities', *Journal Of Strength And Conditioning Research / National Strength & Conditioning Association,* 27(11), pp. 3150-3158. doi: 10.1519/JSC.0b013e31828bf1aa.
Warburton, D. E. R., Nicol, C. W. and Bredin, S. S. D. (2006) 'Health benefits of physical activity: the evidence', *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne,* 174(6), pp. 801.
Welch, W. A.*, et al.* (2013) 'Classification accuracy of the wrist-worn GENEA accelerometer', *Medicine and science in sports and exercise,* 45(10), pp. 2012-2019. doi: 10.1249/MSS.0b013e3182965249.
Welk, G. J. (2002) *Physical activity assessments for health-related research.* Champaign, IL: Human Kinetics Publishers Inc.
Wen, C. P.*, et al.* (2011) 'Minimum amount of physical activity for reduced mortality and extended life expectancy: a prospective cohort study', *The Lancet,* 378(9798), pp. 1244-1253. doi: 10.1016/S0140-6736(11)60749-6.
Westerterp, K. R., Wouters, L. and Lichtenbelt, W. D. M. (1995) 'The Maastricht Protocol for the Measurement of Body Composition and Energy Expenditure with Labeled Water', *Obesity Research,* 3(S1), pp. 49-57. doi: 10.1002/j.1550-8528.1995.tb00007.x.
Westling, E.*, et al.* (2011) 'Use of voter registration records to recruit a representative sample', *J Behav Med,* 34(5), pp. 321-329. doi: 10.1007/s10865-011-9317-9.
World Health Organisation (1992). Manual of the International Statistical Classification of Diseases, and Related Health Problems. Tenth Revision ed. Geneva: WHO.
World Health Organisation (2006) *BMI classification*. Available at: http://www.euro.who.int/en/health-topics/disease-prevention/nutrition/a-healthy-lifestyle/body-mass-index-bmi (Accessed: 25 January 2016).
World Health Organisation (2009) *Global health risks: mortality and burden of disease attributable to selected major risks*. Available at: www.who.int/healthinfo/global_burden_disease/GlobalHealthRisksreport_full.pdf.
World Health Organisation (2010) *Global Recommendations on Physical Activity for Health*. Online. Available at: http://whqlibdoc.who.int/publications/2010/9789241599979_eng.pdf (Accessed: 21 September 2015).
World Health Organisation (2015) *Health topics*. Online. Available at: http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability (Accessed: 19 March 2015).
World Health Organisation, Organisation (2016) *Global recommendations on physical activity for health*.
World Health Organisation (2017a). Global Physical Activity Questionnaire Analysis Guide. Online: Surveillance and Population-Based Prevention of Noncommunicable Diseases Department World Health Organisation.
World Health Organisation (2017b) *Global strategy on diet, physical activity and health*. Online. Available at: http://www.who.int/dietphysicalactivity/en/ (Accessed: 10 October 2017)
www.ipaq.ki.se. (2005) *Guidelines for data processing and analysis of the InternationalPhysical Activity Questionnaire (IPAQ)—Short and long Forms*. Online.

List of Appendices

Appendix 1: Systematic review searches

yetunde's Folder .

OXFORD BROOKES UNIVERSITY LIBRARY

Back

Description

Date Created 1/10/2015

CINAHL ..
MEDLINE .

Databases

Search Strategy S1 AND S4

Interface EBSCOhost

Save Search As e Saved Search (Permanent)

Saved Search

(Temporary, 24 hours)

Alert

Save Cancel

#	Query	Limiters/Expanders	Last Run Via	Results	Action
S5	SI AND S4	Search modes Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database CINAHL	177	Edit
S4	S2 OR S3	Search modes Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database CINAHL	42,174	Edit

S3	"motor activity level" or "motor activity measurement" or "physical activity level" or "physical activity measurement"	Limiters - English Language; Primary Research Articles; Peer Reviewed; Age Groups: All Adult; Human Expanders - Apply related words; Also search within the full text of the articles Search modes Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	392	Edit Name of Search/Alert motor activity level in ID-edited
S2	physical activit* or exercjs* or sport or motor activit* or Exertion or "Physical fitness" or "Exercise	Limiters - English Language; Primary Research Articles; peer Reviewed; Age Groups: All Adult; Human	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	52,660	Edit

	therapy"	Expanders - Apply related words; Also search within the full text of the articles Search modes Boolean/Phrase	Database CINAHL		
S1	intellectual* disab* or learning disab* or mental* deficien* or mental* disab* or mental* handicap*or mental* retard* or mental* subnormal*	Limiters - English Language; Primary Research Articles; Peer Reviewed; Age Groups: All Adult; Human Expanders - Apply related words; Also search within the full text of the articles Search	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	3,174	Edit

modes
Bootean/Phrase

Save Cancel

iPhone and Android apps | EBSCO Support Site | Privacy Policy Tetms of Use | Copyright

Appendix 2: The invitation letter to the Feasibility study

OXFORD BROOKES UNIVERSITY

Invitation letter

Study title: Physical activity in adults with learning disability

Dear Sir/Madam

We are writing to people with a learning disability who are known to the local authorities in Buckinghamshire.

We are writing to ask if you would like to be part of our study. We are doing a study about how we measure movements in people with learning disabilities.

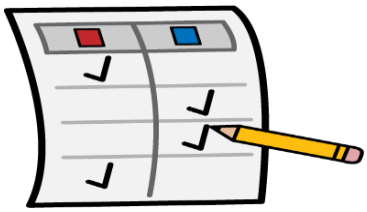
To be suitable to take part, we will ask that:

- you or your carer/relatives understand instructions in English language
- no history of deliberately hurting someone or yourself in the past 12 months

- no broken bone or muscle sprain/strains in the last three months
- no history of brain/spinal cord injury
- no history of skin reactions to things placed on your wrist such as a wrist watch.

If you decide that you want to be part of this study, you would be visited at home and asked to wear an activity meter on your wrist for one week. This activity meter is like a wrist watch (see picture below) and it records general movement.

At the end of the one week, you and your carers/relatives will also be asked to complete a short form detailing how much exercise you do.

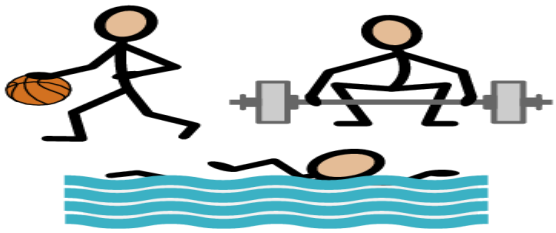


You and your carers/relatives will be asked to return the completed form and the activity meter. You will be provided with a stamped self-addressed envelope which you will use to return them to our research office. You won't need to pay for stamp.

You do not have to be in this study if you do not want to be. If you decide to stop after we begin, that's okay too.

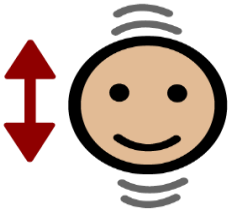
There's no direct benefit for taking part in this study. A benefit means that something good happens to you. We hope that this study results

will improve our understanding of physical activities in people with learning disabilities.



When we are finished with this study we will write a report about what was learned. This report will not include your name or that you were in the study.

If you decide you want to be in this study, please fill in the attached reply slip and return it in the envelope provided. You will not need to put a stamp on this.



Thank you.

Yetunde Dairo

PhD researcher, Oxford Brookes University

Symbols from https://www.n2y.com/products/symbolstix/

Appendix 3: Information about the Feasibility study and a sample consent form

Participants/carers/relatives' copy

Research information sheet

Study title: Physical activity in adults with learning disability

Dear Sir/Madam

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You would be given a copy of this information sheet to keep and for future reference.

What is the purpose of the study?

This study will explore how we measure physical activity levels in people with learning disabilities (also known as intellectual disabilities).

Why have I been invited to participate?

Individuals who are known to Buckinghamshire local authority as having learning disabilities, who live in Buckinghamshire and are 18 years old or over have been invited to take part in the study.

Eligibility criteria

To be suitable to take part, we will ask that you meet the following conditions:

- you or your carer/relatives understand instructions in English language
- no history of deliberately hurting someone or yourself in the past 12 months
- no broken bone or injury to your muscle resulting in sprain/strains in the last three months
- no history of brain/spinal cord injury
- no history of skin reactions to things placed on your wrist such as a wrist watch.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to stop at any time and without giving a reason.

What will happen to me if I take part?

1. You will be visited at home by a researcher. This will last for about one hour.
2. During the home visit, you and your carers/relatives would receive written information about the study and consent form.
3. If you are not able to provide written consent, we will ask someone who has known you for at least 6 months to sign a proxy consent form. Such people can be a family member or a carer.
4. Following consent, we will obtain baseline information and then you would be invited to wear an activity meter (also known as accelerometer) on your wrist for one week, during all waking hours. This activity meter is shaped like a wrist watch and it records general movement. You and your carers/relatives would also receive information/instructions on how to wear and remove the activity meter.
5. At the end of the one week, you will be asked to complete the short, past 7-day, self/carer-administered form of the International Physical Activity Questionnaire detailing your regular physical activity levels. If your carers/relatives sign the proxy consent form then they will be the ones to fill in the Questionnaire on your behalf, detailing your regular physical activity levels.
6. On the 8th day, the researcher will telephone you and/or your carers/relatives to remind you/them to fill in the questionnaire.
7. You will be provided with a stamped self-addressed padded envelope which you or your carers/relatives will use to return completed questionnaire and activity meter to our research office. You won't need to pay for stamp.

What are the possible benefits or risks of taking part?

There's no direct benefit to the participants but we hope that the results will further our understanding of physical activities in people with learning disabilities.

There's no record of harm to anyone who have used the activity meter in the past however, there's a low risk of physical injury to either the participants or their carers/relatives if they hit out at someone therefore, we will not include individuals who are likely to hurt themselves or others.

Will what I say in this study be kept confidential?

All information collected about participants will be kept strictly confidential subject to legal limitations - i.e. it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

Research data will be kept securely at all times and all identifiable information removed.

Data generated in the course of the research will be kept securely in paper or electronic form for a period of ten years after the completion of the research project in accordance with the University's policy on Academic Integrity.

What should I do if I want to take part?

If you would like to take part, you will be given a consent form to sign.

What will happen to the results of the research study?

They will be used as part of PhD dissertation which will be held in the University library and they may also be published in a peer reviewed journal.

Who is organising and funding the research?

The research is being conducted as part of a PhD studies at Oxford Brookes University Faculty of health and life sciences.

Who has reviewed the study?

The research has been approved by the Oxford Brookes University Research Ethics Committee.

For further information please contact:

Mrs Yetunde Dairo OR **Dr Johnny Collett** OR **Prof Helen Dawes**

Faculty of health and life sciences,

Oxford Brookes University

Gipsy Lane, Headington, Oxford

OX3 0BP

Tel: [mobile number has been removed]

Email:yetunde.dairo-2014@brookes.ac.uk OR jcollett@brookes.ac.uk

If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk.

Thank you for taking time to read the information sheet.

Symbols from https://www.n2y.com/products/symbolstix/

OXFORD BROOKES UNIVERSITY

CONSENT FORM Participant Identification Number for this study:

Title of Study: Physical activity in adults with intellectual disabilities

Research team and contact details:

Yetunde Dairo, PhD researcher;

Dr Johnny Collett and Professor Helen Dawes, Supervisors

Faculty of health and life sciences

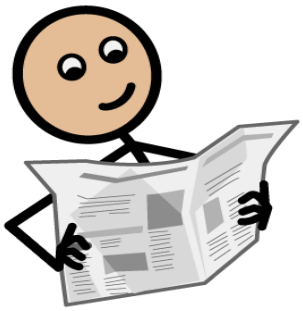
Oxford Brookes University

Tel no: 07584007016

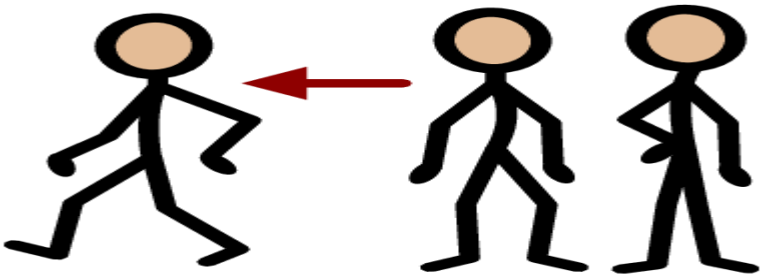
Email addresses: yetunde.dairo-2014@brookes.ac.uk; jcollett@brookes.ac.uk; hdawes@brookes.ac.uk

Please initial box

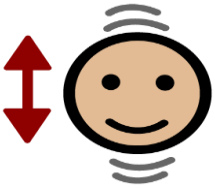
1. I confirm that I have read and understand the information for the above study and have had the opportunity to ask questions. ☐



2. I understand that my taking part is voluntary and that I am free to withdraw at any time, without giving reason. ☐



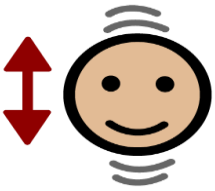
3. I agree to take part in the above study. ☐



Please initial box

Yes ☐ No ☐

4. I agree that my records from this study may be kept (after my name has been removed) in a safe place and may be used for future research.



_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____

Name of Researcher	Date	Signature

Name of Proxy respondent	Date	Signature

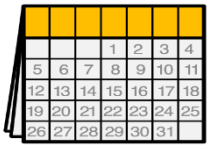
If proxy respondent is signing, please state relationship to participant (e.g. carer or relative):

Symbols from https://www.n2y.com/products/symbolstix/

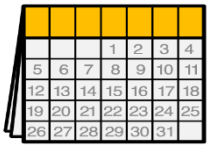
Appendix 4: International Physical Activity Questionnaire-short version (IPAQ-s) with pictures

INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

We are interested in finding out about the kinds of physical activities

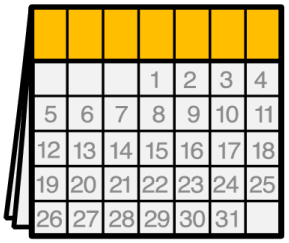
that people do as part of their everyday lives. The questions will ask you about the time  you spent being physically active in the **last 7 days**  . Please answer each question even if you do not consider yourself to be an active person.

Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities  that you did in the **last 7 days**  . **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than

normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

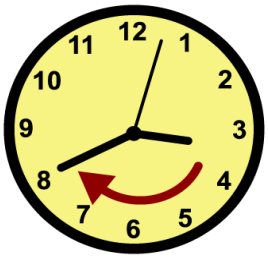


_____ **days per week**

☐ No vigorous physical activities → ***Skip to question 3***

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

_____ **hours per day**



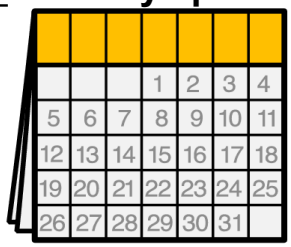
_____ **minutes per day**

☐ Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

_____ **days per week**

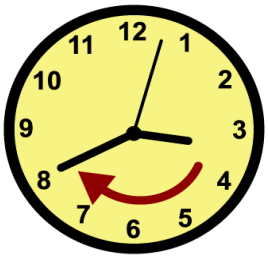


☐ No moderate physical activities → ***Skip to question 5***

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ **hours per day**

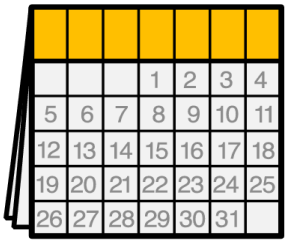
_____ **minutes per day**



☐ Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?



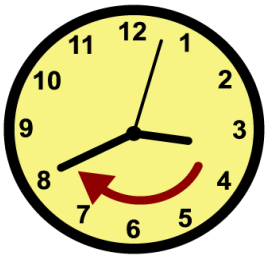
_____ **days per week**

☐ No walking → ***Skip to question 7***

6. How much time did you usually spend **walking** on one of those days?

_____ **hours per day**

_____ **minutes per day**



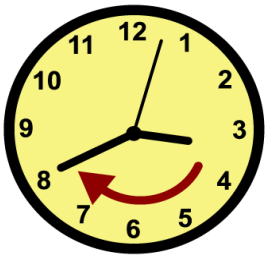
☐ Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

_____ **hours per day**

_____ **minutes per day**



☐ Don’t know/Not sure

Today’s Date:

This is the end of the questionnaire, thank you for participating.

Appendix 5: SOP for the accelerometer monitors (AX3 and GENEActiv)

SOP TITLE: Accelerometer Axivity AX3
Version Number: 1

	NAME	SIGNATURE	DATE
Author	Yetunde Dairo		19/01/2016
Reviewer			
Authoriser			

Version	Date	Reason for Change
1	19/01/16	First version created

This Standard Operating Procedure (SOP) is to be followed by researchers when the Accelerometer Axivity AX3 is used within the Movement Science Group, Oxford Brookes University.

Introduction	AX3 is a data logger. It features a state of the art MEMS 3-axis accelerometer and Flash based on-board memory. The device incorporates a real time quartz clock and temperature sensor. The device is ideal for collecting longitudinal movement data. The Accelerometer AXIVITY AX3 measures linear acceleration from ±2 / 4 / 8 / 16g Configurable along three orthogonal axes known as 'z' (upward and downward), 'y' (left and right) and 'x' (forward and backward). It has a resolution up to 13 bit.
Equipment	Accelerometer AXIVITY AX3

Procedure

Set up

1. Make sure the datalogger is connected to the computer via a micro USB cable (the datalogger has no switch button)
2. Open the programme 'Open movement'
3. Make sure there are no existing data, if there are, click on the sensor's ID number so that it's highlighted and then click 'Clear'
4. Click on the 'Record' button in the programme.
5. On this screen you can apply the appropriate settings. 'Sampling frequency'→ 25Hz (for pragmatic reasons as published work in people with intellectual disabilities did not specify their frequency); 'Range'→ 8g (gravity); choose the recording time the way you want it
6. When the settings are correct, click on 'ok', the sensor is ready for use.
7. Make sure the 'Flash during recording' is clicked.
8. Unplug the datalogger and close the program or use it for another sensor

Calibration

The sensor uses an internal clock and calibration can be done by using the timestamp information.

Run test

Set to start recording on the day participants receive it and to continue recording for a period of seven days and one hour thereafter.

Downloads

1. First you create 'working folder' by going to file then choose 'choose working folder' you only need to do this once.
2. Make sure the datalogger is connected to the computer via a micro USB cable (the datalogger has no switch button)
3. Open the programme 'Open movement'
4. Click on the sensor's ID number so that it's highlighted
5. Click on download
6. The downloaded file appears in the 'Data Files' tab
7. Click on the downloaded data files so that it's highlighted
8. Click on Plugins in the 'Data Files' program functionalities
9. Choose 'convert CWA', then press run
10. The 'RunPluginForm' appears
11. Name the file for e.g use date +Sensor ID and participants' ID
12. Specify the file type - CSV
13. Then in 'Time Format' choose string. Then click on convert now
14. The files will be downloaded to the 'working folder' (see step one).

Further considerations	Record sensors number against participants research ID in CRF.
Miscellaneous	Specifications The AX3 is a combination logging sensor for collecting data in a variety of applications including free-living monitoring of daily behavior. At the heart of the sensor is a state of the art three-axis micro electro-mechanical system (MEMS) accelerometer and a large block NAND flash memory chip linked by a USB enabled microcontroller. A temperature sensor, ambient light sensor, real time clock (RTC) and lithium polymer power source are also integrated into the hermetically sealed plastic encapsulation. The device can be charged in less than 2 hours for up to 21 days continuous recording of all sensor data (source http://axivity.com/files/resources/AX3-User-Guide-v1-2.pdf accessed 22-01-16).

SOP TITLE: GENEActiv Monitor
Version Number: 3

	NAME	SIGNATURE	DATE
Author	Dax Steins		10-04-2012
Reviewer	Yetunde Dairo		01-04-2016
Authoriser			

Effective Date:	
Review Date:	01-04-2016

Version	Date	Reason for Change
2	01-04-2016	To edit, update, and clarify data download and conversion as well as to add instructions on how to covert physical activity data from the CSV file into physical activity levels..
3	12-12-2016	To clarify data conversion for sedentary hours.

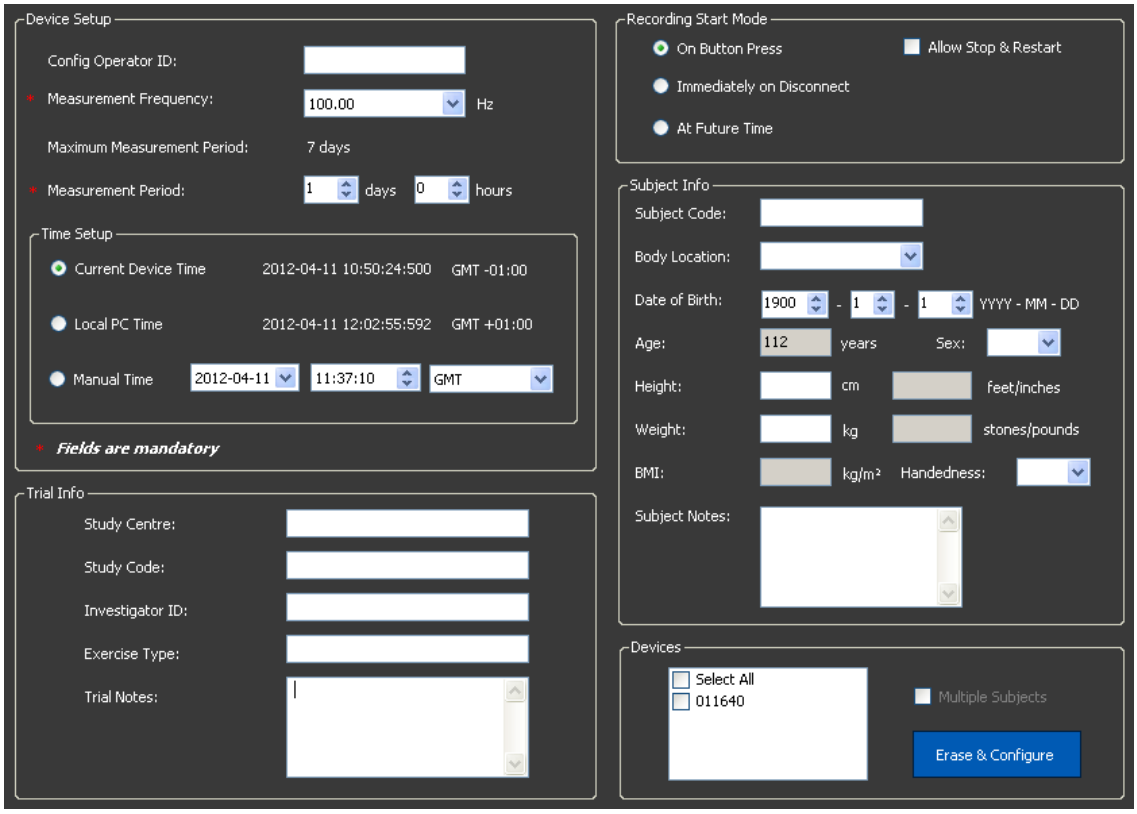
This Standard Operating Procedure (SOP) is to be followed when using **the GENEActiv activity monitor** with the Movement Science Group, Oxford Brooks

University.

Introduction	*Brief introduction including references for validation / recommended guidelines* The **GENEActiv** is reliable body-worn triaxial acceleration sensor and is a relatively simple device to use, however, it is important to know how to properly configure this device to obtain physical activity data.
Equipment	- USB cable - Cradle - Interface software CD or download PC software from http://www.geneactiv.org/resources-support/downloads-software/ - GENEActiv sensor **System requirements:** - PC with Intel P4 Processor, 2Gb Memory - Windows XP, Vista or 7 - .net Framework 3.5
Procedure	1. Connect the GENEActiv charging cradle to a USB port and plug in a single GENEActiv device. Make sure that the device 'clicks' into place (if it has a strap fitted, the strap may need to go behind the mounting clip to ensure a good connection)
	2. Start the GENEActiv PC Software. 
	3. The software should recognize the GENEActiv. This is displayed on the left bottom window with its specific serial number.

4. Make sure that before you start with any measurements the battery is 100% whilst memory status 0%. **IMPORTANT** If the memory status is not 0% it contains recorded data.

5. Click ‘Config. Setup’ from the left-hand menu. This page (see below) allows you to set recording options and enter information about the trial and test subject. A few fields must be completed for the device to operate (as listed in point 6 below); the rest can be filled in where appropriate. **IMPORTANT** Before you can erase and configure the GENEActiv device you will need to fill out the complete setup.



	6. Select ‘Measurement Frequency’ (the measurement frequency selected will determine the maximum time data can be recorded a lower frequency = longer time). - Select ‘Measurement Period’ (this can be anything between an hour, and the maximum period displayed just above). - Select ‘Local PC Time’ - Select when you want the recording to start, ‘On Button Press’, ‘Immediately’ on ‘Disconnect’, or ‘At Future Time’. If you select ‘On Button Press’, a further option, ‘Allow Stop and Restart’, will appear. This is useful for lab experiments but during actual user trials could lead to recording being stopped by an accidental button press. The button is hidden under the serial number and requires a firm press to avoid accidental activation. - Enter any further information as required (note that some fields such as Age and BMI are self-calculating).
	7. To configure the GENEActiv and get it ready to record, select the serial number of the device in the Devices box in the bottom right-hand corner of the screen (the serial number is printed on the front of the device) and click Erase & Configure.
Reading Data	1. Insert a GENEActiv device into the cradle. Click ‘Data Extractor’ from the left hand menu (see below). This page previews the first few minutes of recorded data and allows you to download data to a chosen file location. 2. Chose a file location and select whether to also create a .csv format file. The default data format is a

	compressed .bin that can be interpreted, with a suitable script, by most mathematical analysis software packages, but not Excel. A .csv format file is readable by Excel, but can be unwieldy if there is a large amount of data. The Data Converter and Data Analysis tabs (selected from the left-hand menu) can convert .bin files to .csv files or to compressed .csv files that can be handled more easily. This means that .bin files can be saved and then converted to another format at a later date if required. 3. Saving the BIN file, click browse and then formats the file name. Use the accelerometer number (comes up automatically), participants initials and date of download for ease of reference. 4. Click the 'Extract' button.
Data Converter & Data Analysis	The 'Data Analysis' tab has a viewer which allows data from .bin and .csv files to be previewed. There is an option to look more closely at sections of the data. The 'Epoch Converter' can be used to turn .bin and large .csv files into a smaller compressed version. It does this by creating epochs of 1, 5, 10, 15, 30, or 60 seconds – the means for each parameter and the Sum Vector Magnitude are calculated for each epoch. Data conversion steps : 1. Select data converter, browse and select the BIN file saved above (as explained in 'data reading'). 2. Then select 60 seconds Epoch period 3. Browse 'select outputs.CSV file and save the file. Use participant's identification number, initials and the date the accelerometer was issued for example 01YD01042016. 4. Now click convert

Further considerations	To convert the .CSV file into meaningful physical activity (PA) levels (determined by the amount of time spent in a specified PA intensity threshold range), categorised as sedentary, light, moderate, and vigorous, you can use the MSG Analysis 60 epoch, an in-house excel program, by following the instructions below: **INSTRUCTIONS FOR USE:** When epoched the file in 60 seconds via the GeneActive software, follow the next few steps: 1) Open the epoched .csv file 2) Select and copy column A to L 3) Copy them in columns A to L on the left Columns and Rows are automatically generated in the table below NOTE: Changing the code will result in faulty table, graphs and figures
Miscellaneous	Although we select measurement period as 8 days, we use 7 days and one hour. We delete the excess data after using the 'MSG Analysis 60 epoch' (MSG excel program). Sedentary hours: Day two of accelerometer data is used as day1 for the sedentary data; therefore, there will be 6 full days and then data from day one of the accelerometer data will be added to the day seven to make the 7th day for the sedentary data. Where there's overlap between day seven and day one data, the fisrt hour of day one will be deleted.

To calculate sedentary hours per day, use excel formula COUNTIF (COUNTIF range, “condition”) and the divide the output by 60 as the data was collected in minutes. The day time hours used was 8am to 9pm

Dr Johnny Collett
Director of Studies
Department of Sport and Health Sciences
Centre for Rehabilitation
Faculty of Health and Life Sciences
Oxford Brookes University
Gipsy Lane
Headington

15 December 2015

Dear Dr Collett

UREC Registration No: 150967
Physical activity in adults with intellectual disabilities

Thank you for the email of 10 December outlining the response to the points raised in my previous letter about the PhD study of your research student Yetunde Dairo and attaching the revised documents. I am pleased to inform you that, on this basis, I have given Chair's Approval for the study to begin.

The UREC approval period for this study is two years from the date of this letter, so 15 December 2017. If you need the approval to be extended please do contact me nearer the time of expiry.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

Yours sincerely

Dr Sarah Quinton
Chair of the University Research Ethics Committee

cc Helen Dawes, Second Supervisor
Yetunde Dairo, Research Student
Dido Green, Research Ethics Officer
Jill Organ, Research Degrees Team
Louise Wood, UREC Administrator

Appendix 7: Ethics amendment approval for the cross-sectional study

OXFORD BROOKES UNIVERSITY

Yetunde Dairo
PhD Student
Department of Sport and Health Sciences
Centre for Rehabilitation
Faculty of Health and Life Sciences
Oxford Brookes University
Headington Campus

22 June 2016

Dear Yetunde

UREC Registration No: 150967
Physical activity in adults with intellectual disabilities

Thank you for your email of 15 June 2016 requesting some minor changes to the original study approved by UREC on 15 December 2015.

I confirm that you wish to invite all participants to complete the physical activity questionnaire and the accelerometer will be offered as an optional stage of the study. You would like to add a question about sitting to the questionnaire and also to extend your recruitment to Oxfordshire. Thank you for providing updated documentation for these changes.

On this basis I give Chair's approval for this change. The UREC approval remains the same as the original study, so until 15 December 2017. If you need the approval to be extended please do contact me nearer the time of expiry.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

I wish you continued success with your research.

Yours sincerely

Dr Sarah Quinton
Chair of the University Research Ethics Committee

cc Johnny Collett and Helen Dawes, Supervisory Team
Dido Green, Research Ethics Officer
Jill Organ, Research Degrees Team
Louise Wood, UREC Administrator

OXFORD BROOKES UNIVERSITY

Yetunde Dairo
PhD Student
Department of Sport and Health Sciences
Centre for Rehabilitation
Faculty of Health and Life Sciences
Oxford Brookes University
Headington Campus

13 September 2016

Dear Yetunde

UREC Registration No: 150967
Physical activity in adults with intellectual disabilities

Thank you for your email of 31 August 2016 requesting some minor changes to the original study approved by UREC on 15 December 2015.

I confirm that you have made two minor additions to the physical activity questionnaire, supplied as version 2 dated 31 August 2016. I am pleased to give Chair's approval for this minor change. The UREC approval remains the same as the original study, so until 15 December 2017. If you need the approval to be extended please do contact me nearer the time of expiry.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

I wish you continued success with your research.

Yours sincerely

Dr Sarah Quinton
Chair of the University Research Ethics Committee

cc Johnny Collett and Helen Dawes, Supervisory Team
Anne Delextrat, Research Ethics Officer
Jill Organ, Research Degrees Team
Louise Wood, UREC Administrator

OXFORD BROOKES UNIVERSITY

Yetunde Dairo
PhD Student
Department of Sport and Health Sciences
Centre for Rehabilitation
Faculty of Health and Life Sciences
Oxford Brookes University
Headington Campus

25 October 2016

Dear Yetunde

UREC Registration No: 150967
Physical activity in adults with intellectual disabilities

Thank you for your email of 13 October 2016 requesting some minor changes to the original study approved by UREC on 15 December 2015.

I confirm that you have amended the invitation letter to make it clear for participants that by completing and returning the consent form they are agreeing to take part in the study. The final paragraph has been amended to remove details about the collection of accelerometer data, and you will administer section three of the physical activity questionnaire twice to check intra-rater reliability. An updated copy of the invitation letter has been provided as an adequate audit trail.

I am pleased to give Chair's approval for these minor changes. The UREC approval remains the same as the original study, so until 15 December 2017. If you need the approval to be extended please do contact me nearer the time of expiry.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

I wish you continued success with your research.

Yours sincerely

Dr Sarah Quinton
Chair of the University Research Ethics Committee

cc Johnny Collett and Helen Dawes, Supervisory Team
Anne Delextrat, Research Ethics Officer
Jill Organ, Research Degrees Team
Louise Wood, UREC Administrator

Appendix 8: Construct Validity - SPAIM

Participant Identification Number: Date:

Evidence of the construct validity of the Physical activity intention measure

1. How long is 30 minutes?

Which of these activities last for 30 minutes? (Please tick one)

☐ Watching EastEnders/ Coronation street/ your favourite TV soap
☐ Playing/watching football or watching a film
☐ Listening to the weather forecast

2. What do you understand by 'standing or moving around'?

Note: For example playing on a play station would be wrong, equally, rock climbing will indicate that they perceive the activity question wrongly

Appendix 9: The IPAQ and SPAIM survey

PHYSICAL ACTIVITY QUESTIONNAIRE

Dear Sir/Madam

We are conducting a representative survey of carer/family/individuals with learning disability regarding the physical activity levels of adults with learning disabilities.

The survey would take about 10 minutes to complete.

A Freepost envelope is enclosed for your completed survey.

All questions contained in this questionnaire are optional and will be kept strictly confidential.

SECTION 1
BASELINE INFORMATION

Age: **Height (if known):** **Weight (if known):**	**Sex:** Male ☐ Female ☐ **Race:** White☐ Black☐ Asian☐ Mixed☐ Others (please state):

Learning disability severity: Mild ☐ Moderate ☐ Severe ☐ Profound ☐ Not known ☐

Employment: Yes ☐ No ☐

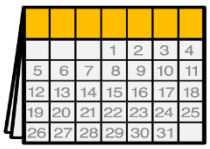
Residence: Alone ☐ With family ☐ Supervised care ☐ Residential home ☐
Others (please state):

Mobility: Walks independently ☐ Needs assistance ☐ Wheelchair user ☐

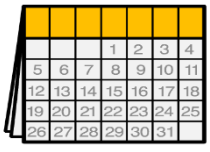
Do you have high blood pressure?	Yes ☐	No ☐	Don't know ☐
Do you have high cholesterol levels?	Yes ☐	No ☐	Don't know ☐
Do you have diabetes?	Yes ☐	No ☐	Don't know ☐

SECTION 2
INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

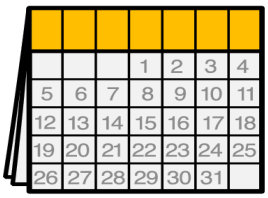
We are interested in finding out about the kinds of physical activities

that people do as part of their everyday lives. The questions will ask you about the time  you spent being physically active in the **last 7 days**  . Please answer each question even if you do not consider yourself to be an active person.

Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities  that you did in the **last 7 days**  . **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

5. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

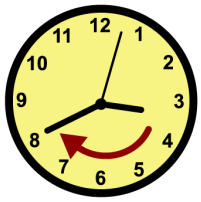


_____ **days per week**

☐ No vigorous physical activities → ***Skip to question 3***

6. How much time did you usually spend doing **vigorous** physical activities on one of those days?

_____ **hours per day**

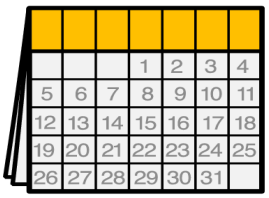


_____ **minutes per day**

☐ Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

7. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

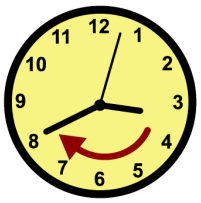


_____ **days per week**

☐ No moderate physical activities → ***Skip to question 5***

8. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ **hours per day**

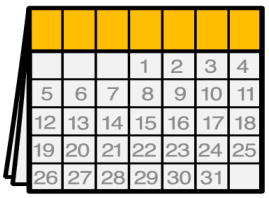


_____ **minutes per day**

☐ Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

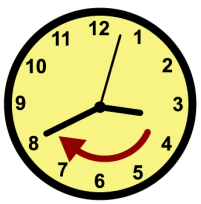


_____ **days per week**

☐ No walking → ***Skip to question 7***

8. How much time did you usually spend **walking** on one of those days?

_____ **hours per day**



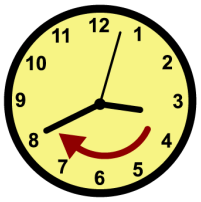
_____ **minutes per day**

☐ Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

9. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

_____ **hours per day**



_____ **minutes per day**

☐ Don't know/Not sure

SECTION 3
PHYSICAL ACTIVITY INTENTION

I would like to get up from my seat and do something that involves either standing or moving around, for a minimum of 30 minutes, at least 5 days in a typical week.

Very unlikely	Unlikely	Neutral	Likely	Very likely
☐	☐	☐	☐	☐

Today's Date:

This is the end of the questionnaire, thank you for participating.